CHAPTER 4

THE IMPACT OF AIDS ON THE FAMILY SYSTEM

> *"A person with AIDS and his/her family share one thing in common: Their lives are never the same once a diagnosis of AIDS is confirmed" (Walter E Smith 1988:136)*

4.1 INTRODUCTION

The following story was told by a mother of a Sowetan family I have been visiting for the last five months, who recently lost her daughter, (Purity). I met Gladys in June 2001, during my second visit at the Baragwanath Hospital.

I had every reason to be proud of my daughter. She was a good single mother of two, a primary school teacher and a person with lots of respect for her parents. Her friends loved her. Purity was the youngest of seven children.

In September last year – just before the school holidays, Purity arrived home from school very tired. It was almost time for her to celebrate her womanhood (menstruation). I doctored her with some herbs, and told her to get into bed. After a few days she developed a sore throat and dry cough from which she did not seem to be able to get rid of. She went to see a doctor. The school holidays started. It came as a relief ... so we thought ... During the following two weeks my girl became very strange – she started to become very irritable ... it was one outburst after the other ... She lost weight ... had a daily *problem with her tummy (had diarrhoea).*

After a week or so, she became very worried about herself and decided to go to the doctor ... I wish she never went. Many tests were done. The following day the doctor said to her: "Well, we found AIDS antibodies in your blood". Since these cold words were spoken – our lives as a family has never been the same. Many questions crossed my mind. "How are we going to keep her illness for ourselves?" "What will her friends and colleagues say?" "Where are we going to get money?" "What am I going to tell her children?" I had many, many questions.

It was not easy ... I don't wish this experience on my worst enemy ... It's a hard and lonely road. Maybe I should not say it, but I feel relief ... she suffered, no, all of us suffered a lot ... I think she is better off where she is now – much better.

Walter & Smith (1988:135) capture the dynamics of the above story in perspective as they describe the impact of AIDS on the family as follows:

> For every person who contracts AIDS, the entire family circle carries the consequences of that person's disease with them and carries, as well, the consequences of the AIDS person's decisions to live hopefully or die despairingly. For every lover and every friend, for co-workers and health professionals, the AIDS person (not victim!)

> stands as a mirror for all our fears about disease, about death, about pain, about loss. Each one of us is confronted daily by our own deepest fears, our own personal response to life and death, our own choices to run away or to stay and love …

This quotation puts emphasis on the fact that HIV/AIDS is a family syndrome and that it has its impact not only on the person whose body is infected with the deadly virus, but on each other person with whom he or she shares important relationships. Everyone involved may feel trapped, and unable to alter the inevitable course of events. Gladys' story, like others, made me realize that the family is a unit of interacting personalities and that any disruption or dysfunction in the life of the family will be disrupted and felt in all other aspects of the family unit.

In this chapter I will examine, explore and discuss the experience of the family system and HIV/AIDS through the perspectives of people living with HIV/AIDS and their families. The following aspects will be focussed on: *The family in crisis as a result of HIV/AIDS; The various stresses on the family system as a result of AIDS; The impact of HIV/AIDS on family members; The characteristics of a family being affected by HIV/AIDS;* and lastly; *The aspect of grief and bereavement in the family.*

4.2 THE FAMILY IN CRISIS AS A RESULT OF HIV/AIDS

4.2.1 The crisis

Kavar (1988:23) describes "**crisis**" as follows:

> The sudden, unexpected interruption of life's normalcy that we know as crisis is fraught, with various, after conflicting emotions. This triggers emotions like treat, shock, fear, anger, hesitation, disbelief, hope ...

As I was listening to Gladys' story I came to the conviction that there is no doubt that HIV/AIDS has the potential to make the infected and affected feel handicapped and overwhelmed by some thing, which seems to be stronger than themselves. The inability to cope with this sudden, unexpected interruption paves the way for a possible crisis to develop.

Kavar (1988:23) sees "crisis as a dangerous opportunity". It can therefore be argued that a crisis can potentially be viewed as dangerous, but also "as a very special opportunity for growth" (Louw: 1994:I). The conclusion we can come to is that different people in different situations can experience a crisis differently.

4.2.2 The experience of the crisis

In my interviews with those infected as well as those affected, I have discovered that the crisis event varied and so did the degree of emotional intensity. Following are a few lines, which illustrates some of the crisis events and degree of emotional intensity as it was experienced and expressed by different companions during interviews I've had with them.

- ***The crisis experienced at the reception of the news***

> *I could not think properly … everything suddenly turned blank. I think I've lost myself completely for months … I could not cope, but I also did not want to cope. I did not have the energy to even bother to cope …*

- ***The crisis experienced during a time of personal alienation***

> *I am a very strong person, but when my friends, colleagues and even family members started to move away from me, I broke into pieces. It was easier for me to cope with the news that I was HIV positive … I had a suspicion of such a possibility. But I felt like dying when*

my friends stopped kissing and hugging me … I just could not cope with that.

- ***The crisis experienced during the caring stage***

My pa was a regte don-johan onder die hoenders. "Hou-vrouens" was sy "hobby". Toe ons uitvind hy is HIV positief, was ons glad nie verbaas of eers geskok nie. Waarmee ons nie kan "cope" nie, sy "moodswings" – dit dryf ons almal "nuts".

- ***The crisis experienced during the dying stage***

It would have been better if I or any other adult, family member, for that matter were dying … not my child. That was the hardest thing to experience … seeing my boy "disappearing" in front of my eyes. It was disturbing to see him so helpless in the face of death.

- ***The crisis experienced without the person***

Na sy dood het ek uiteindelik besef watter groot rol hy in ons gesin se lewe gespeel het. 'n Basiese ding soos om sonder hom te eet, was meer as net 'n gevoel van

> *vermisting, vir ons was dit 'n krisis ... Simple goed soos shopping, betaling van bills is glad nie meer so simple vandat ons dit self moet doen ...*

- ***The crisis experienced as positive***

> *Our family never stood with each other in the way they do now. You should have seen what this family was looking like before we found out about my fathers' illness. It was scattered. AIDS forced us together.*

It is therefore of critical importance for those working with the *infected* and *affected* members to maintain a certain awareness of the different contexts in which a crisis could be experienced and not just randomly assume that everyone experiences a crisis in the same way and at the same point with the same effect. In my dealings with these families, I have discovered that which is a crisis for one is not necessarily a crisis for the other.

4.3 A FAMILY RESPONSE TO THE CRISIS

In my involvement and direct dealings with both the infected and affected I've come to the realization that no matter how a particular crisis event is experienced, no matter the degree of emotional intensity in the time of the crisis, the phenomenon of the crisis by nature hurls people into the making of a decision, either a positive or a negative one.

Kavar (1988:30) writes:

> The experience of crisis is overwhelming. The human response to being overwhelmed tends to fall into two categories, "*fight*" or "flight".
>
> (Italics mine)

These responses are not uncommon, and inappropriate, in fact, it offers service as a necessary "tool" towards the restructuring and eventually re-authoring of the problem saturated area, which normally builds up to the crisis in the companion's story. These two responses will now be discussed as viewed by Kavar (1988:30-36).

4.3.1 The "fight" response

According to Kavar (1988:30) "fighting the crisis of AIDS may take several forms". Some of these forms had been discussed in previous chapters and will therefore be just mentioned in short here. Fighting may be expressed as:

- **Anger** directed at caregivers, other family members, the person with AIDS, society, the Church or virtually anyone or anything else. As devastating as this anger may seem, it is a sign of movement, of hope

- and of a certain capacity to attack the problem of HIV/AIDS. This anger can be used as a source of energy to be tapped in order to direct the companions' story towards a positive re-authoring, through the process of externalization. (externalization is discussed in depth in chapter 6)

- **Direct mobilization**. In this potential fight response, the family members may begin almost immediately to seek out "the best possible care". This will mean varying things for different family systems. This can easily lead to:

- enmeshment
- over protectiveness
- a family secrecy "club"
- over dependency, et cetera

This direct and conscious mobilization of family members against HIV/AIDS can be positively directed in the recruiting of a support system. The *fight* response can therefore be interpreted as a hopeful sign.

4.3.2 The "flight response

Kavar (1988:31) views the "*flight*" response of the family as "the result of the harshness of reality breaking into one's experience … in a way, which is incomprehensible to or incongruent with one's worldview"

This should not necessarily be interpreted as an unhopeful or negative response. This response often serves as a safety valve or hole in the pressure cooker that prevent the safety valve from bursting. It therefore serves as the safety valve which allows enough steam to dissipate from the experience in order to make it possible for the family members to begin to see their experience, their clouded story more clearly. It can also have the opposite effect. It might also lead "to a rigid, fixed stance that does not allow for a new perspective ..." (Kavar 1988:31). This response was very common in almost all the families interviewed and in many instances lead to:

- abandonment
- rejection
- disownment
- disengagement
- neglect of family members, but also of any other support and support systems.

The "*flight*" response is often a result of:

- fear
- being uninformed
- being deformed
- being misinformed
- misconceptions

- lack of support
- social discourses (e.g. prejudice or judgemental society)

Both these responses create enormous opportunity for the therapist to minister to the family in crisis.

4.4 STRESSESS EXPERIENCED BY THE FAMILY AS A RESULT OF HIV/AIDS

Sharon Lewis (1999:5) is of the opinion that "people feel stressed when they do not have the ability to cope with the physical or emotional demands of a particular situation".

Wanda Nesh (1997:16) describes what stress is, in more particular terms as she writes:

> Stress concerns the feeling of being pushed or squeezed or pulled or stretched. The pressures, weights, burdens that produce these reactions are called stressors, and they often came in the front of challenges to be met and decisions to be made.

The common phrase I have heard in almost all the stories I have listened to was:

"***I CANNOT COPE …***". This refers to the emotional, physical, spiritual, financial and social inability to cope. The infected and affected normally experience a combination of these inabilities. This strong emotion is also very vivid in Gladys' story.

It can therefore be argued that when a doctor tells a person that he/she has AIDS or is infected with HIV, a series of adjustments be set in motion, adjustments that affect every aspect of the persons' life such as family relationships, romantic involvements, friendships, finances, occupational ties, as well as social and spiritual networks. The person, as well as the family's perspectives and priorities, decisions and future plans may change. These adjustments make life for both the person living with HIV/AIDS and his/her family inherently stressful. There is much wisdom in Mullers' (1996:141) words as he writes: "In n gesin word al die lede geraak by die verandering by een lid". The various stresses HIV/AIDS has on the family will now be briefly looked into.

4.4.1 Stress caused on the family by an AIDS diagnosis

Walter & Smith (1988:136) writes:

> A person with AIDS and his or her family share one thing in common: their lives are never the same once a diagnosis of AIDS is confirmed. A person with AIDS wakes up and retires each day, confronted with the realities of the disease; involved family

> members face the same daily prospect. A life-threatening illness modifies the values and perspectives of both the afflicted person and those individuals in his or her life who are most closely related to him or her.

In March 2001,one of our old boys' (at St Stithians College) died of AIDS. As school counsellor I had the wonderful privilege of journeying with the family. Following is a brief "shot" from our conversation.

Counsellor: *Would you like to tell me more about the morning when you felt like a "zombie"?*

Sharol: *That was the morning when my son told me that he had been diagnosed with AIDS … I could not believe what I was hearing. I started to cry hysterically on him … told him that he is only 24, has just completed varsity and has just started a well-earned job … I then went to my bedroom, but I couldn't sleep or cry or think, smell or feel, for many days I was merely existing … a complete zombie. I was tired, but could not sleep; I was hungry, but could not get anything in; I was thirsty, but could not drink anything …*

From Sharol's response we can come to the conclusion that learning about a loved one's diagnosis with HIV/AIDS can be inherently stressful. This knowledge can catalyse a number of physical and emotional responses. (These responses will be elaborated on under 4.4.2; 4.4.3 and 4.4.4)

4.4.2 Physical stress on the family system

Caring for a person living with HIV/AIDS can be physically very draining. Like other chronic, life-threatening illnesses, HIV/AIDS makes enormous demands upon the physical reserves of those infected as well as those affected. From the interviews I have conducted it became clear that family members who assume the role and functions of principal care-providers soon realize the effects the disease has on them.

The following case underscores some of the problems that family members experienced in assisting an infected individual. The following story underpins the problems of a spouse who assisted her haemophiliac husband during his two-year battle with the disease. Johanna, 40 and Willy, 41, a Noordgesicht couple (a so called "coloured" suburb about 5 km from Soweto), had been married for nine years, when Willy at the age of thirty-nine, was diagnosed with AIDS in July 1998. They were a typical young, Afrikaans speaking couple, engaged in dual careers. Johanna is working as a secretary at a Law company in Johannesburg, whilst Willy was working at the VISTA campus in Soweto as an assistant technician.

Ons het 'n redelik gemaklike lewe gelei tot die dag toe ons hoor van sy siekte. Ek het baie hulp van my familie en vriende gekry, maar dit kon regtig nie opmaak vir hoe ek meeste van die tye gevoel het nie. Nog voor ons presies geweet het wat regtig fout was, was dit alreeds baie "demanding". Hy het *enige oomblik van die dag of nag siek geword en ek moes los waarmee ek ookal besig was. Baie kere moes ek verlof insit of net van die werk weghardloop om hom by 'n dokter te kry. Die dokters kon nie presies vasstel wat verkeerd was nie ... Dit was nou vir jou stresvol, maar nie naastenby so stresvol soos toe ons hoor hy het VIGS nie.*

Die ergste het begin die dag toe die dokter ons inroep en ons se wat presies die probleem was. Willy was depressief en het begin kwaad word vir die geringste dingetjie. Sy "moodswings" was die ergste ... dit het my regtig moeg gemaak. In April 1999 moes hy ophou werk. Die dae wat daarna gevolg het was erg. Alhoewel ons hulp van die Mafolo kliniek sowel as Baragwanath hospital in Soweto ontvang het, het hy altyd "demand" en "insist" dat ek dinge vir hom moes doen. Alles, van water aandra, medisyne gee, hospital toe neem, kos maak en aandra, was en skeer ... moes ek doen. Die tye wanneer ek wel by die werk was, moes ek in elk geval gedurende my "tea breaks" huis toe gaan. Hy het geweier dat die kliniek mense die basiese dinge vir hom doen.

Ek het gevoel ek moes dit doen omdat hy ook maar net 'n slagoffer was. Ek bedoel, hy het as gevolg van sy siekte AIDS odgedoen en nie as gevolg van rond slapery nie. Om die waarheid te se, ek weet nie wat van my sou geword het as hy een maand langer moes geleef het. Ek weet dit is lelik om so te dink en te voel, maar dis regtig hoe ek gevoel het.

As we can notice from the above story, the caring process can be very exhausting and distressing on the whole family. Physical exhaustion can in turn raise many other responses such as:

- Headaches
- Inability to sleep
- Stomach upset
- Loss off appetite
- Loss of weight
- Sporadic tiredness
- Numbness
- Tension
- Experience difficulties in concentrating on basic tasks
- Short temper

A lot of the physical fatigue and stress the family members experience, I would argue is often self-inflicted. As in the above case, many family members take on the role of *dysfunctional rescuers*. In other words they perpetuate the already existing problem by seeing their role as totally self-giving to the sick member and as a result stop caring for themselves. The following are ways in which they take on such a dysfunctional and self-inflicted role upon themselves. By:

- *Allowing the infected member to control and dictate their feelings and actions.*
- *Opening up space for other family members as well as the infected to reinforce their sense of obligation.*
- *Not allowing them to be supported (consciously or unconsciously).*
- *Allowing the infected to grow overly dependent on them.*
- *Developing an attitude that they are the only ones who can provide care in a way that will satisfy the infected person.*
- *Allow emotions to derail them from making realistic and rational decisions.*

The pastoral therapists' role here is perhaps to help the person to untangle from the net he/she has caught him/herself in. The therapist should enable the person to become aware of the cul-de-sac he or she finds him/herself in and to explore alternatives, which will lead to a more, balanced caring approach.

4.4.3 The emotional stress on the family

The interview I've had with Johanna, from Noordgesicht, puts emphasis on some of the common emotional stresses caused by HIV/AIDS on the family.

Therapist: *Jy sê jy weet nie wat van jou sou geword het as Willy 'n maand langer moes geleef het nie …*

Johanna: *Jy sal nooit verstaan hoe stresvol dit was om saam met hom en sy siekte te gelewe het nie.*

Therapist: *Gee jy om om my 'n bietjie meer te vertel van die stresvolle tyd saam met "hom en sy siekte", soos jy dit noem.*

Johanna: *Dank die vader ons het nie kinders nie. Ek weet nie hoe hulle dit sou hanteer het nie. Die geringste dingetjie het hom geirriteer en laat kwaad word … nie bietjie kwaad nie, sommer woedend. Soos ek reeds gese het – ek moes hom met alles help. In die begin het hy hom even vererg wanneer ek hom na die hospice moes neem – hy het geglo die dokter is 'n kwaksalwer – en dat hy net griep het. …Kerk mense! Wou hy nie sien nie … Ek het eendag sy boss laat kom om net vir hom 'n bietjie company te keep, dit was die grootste fout. Hy het hom in sy kamer toegesluit en geweier om die deur oop te maak … Agterna was ek al van die lelikste uitgeskel …*

Therapist: *Ek wonder wat dit aan jou gedoen het.*

Johanna: *Ek het baie kere gewens hy moet sterwe sodat alles kan verby wees… Sommige dae het ek hom baie jammer gekry ander dae was alles weer normal en my hoop het opgevlam … somige kere het dit gevoel ek raak gewoond daaraan – ander kere het dit net te veel geword … Dit het soos 'n rond-om-tallie gevoel.*

Therapist: *'n Rond-on-tallie?*

Johanna: *Mm … alles het my sommer net siek en naar laat voel.*

Therapist: *Mmm …*

Johanna: *Dit het my moeg gemaak, kwaad en hartseer laat voel … ek was baie bekommerd oor hom … Ek dink ek het die slegste gevoel … ek het sleg gevoel omdat ek soms lelik was teenoor hom …*

Many of the family members I have interviewed told me about the many feelings they are experiencing as they care for an infected family member. As we have seen in the above interview, these feelings range from being sad, frustrated, discouraged, anger, stressed, isolated depressed, helpless, powerless, tired, et cetera. These feelings cause tremendous stress on the family.

As I was listening to different stories, I have realized that different individuals and families experienced different feelings differently. It is therefore of critical importance to refrain from generalizing and stereotyping these feelings.

There is no doubt that HIV/AIDS constitutes an enormous emotional stress on the family system. Some of the most common feelings precipitated by the disease will now be outlined. I have already elaborated on some of the emotions in chapter 3 and will therefore concentrate on the following:

- *denial (see chapter 3.4.1)*
- *anger (see chapter 3.4.2)*
- *depression*
- *isolation*
- *guilt*
- *grief*
- *fear*
- *helplessness and powerlessness*
- *worrying*
- *despondency (disencouragement)*

- ***Depression***

At my second visit at Baragwanath hospital in July 2001, one of the nursing staff took me to a man called, Zola, who was admitted two weeks before my visit. When I first entered the ward, I noticed that he was lying in his bed, staring at the ceiling. He appeared motionless and weak. The nursing sister told me that he was suffering from severe depression. She also told me that his brother is a committed Christian and that he and people from his church are visiting on almost a daily basis. It was clear to me that although his brother and the church people have been supportive, he felt alone. After almost an hour of me just sitting and holding his hand, Zola started to smile. I told him who I was, and the unexpected happened – he told me his name.

Christensen (1991:149) captured the depression state of an infected person beautifully as he writes:

> ... depression brings the awareness of impending separation and loss. AIDS patients often speak (or passively express, I would say) of "losing ground" and "giving into the process".

The person shows signs of sadness, helplessness, hopelessness and despondency. The family may often feel "off" because of the depression of the infected. Mace & Rabins (1991:211) writes: "The experience of being depressed is painful, we feel miserable and wish for relief from our sad feelings". The stress caused by depression often "forced" family members to find temporarily relief in alcohol, pills, sleeping tablets, et cetera. This leads to even more stress on the family system.

- ***Isolation***

Almost all the families I have interviewed regard isolation, whether inflicted or self-inflicted as extremely stressful. As one said: "*Many people got AIDS, but not many people are prepared to carry the burden*". Many families choose to carry the burden all by themselves, because of the stigma attached to HIV/AIDS. All the families I've interviewed have initially chosen not to make the illness of the infected public. Some have even kept the information from other family members and relatives. All of them experienced, that the secrecy, however served to increase probing and pressure and that it had cut of the infected as well as those affected from necessary support systems and by so doing intensified the problem of alienation, isolation and stress on the family. Sunderland & Shelp (1990:74) reinforces the above point as they write: “Many patients (and families) keep their infection secret from family members and close friends, creating additional barriers that may intensify isolation when support is most needed”.

The immediate family, who chooses this route, may be disenfranchise from extended families, friends, the Church and other mainstream contacts. The experience of self-inflicted or social alienation elicits feelings of isolation, abandonment, despair and extreme stress on the entire family relationships.

- ***Guilt***

The daughter of one of the families said: *“I loved ballroom, but I had to give it up, because I was feeling too guilty enjoying myself whilst my mother was dying at home*”. Guilt is a common feeling experienced by family members. Following is a few guilt expressions I’ve heard in my interviews with family members:

- *"Ek voel skuldig omdat ek voel dinge te veel raak vir my om mee te cope"*

- *"I often felt guilty when I was visiting my friends, knowing that my brother was sick at home".*

- *"I felt terrible when I had to work overtime and not being able to go to the hospital as often as I would wanted to".*

Family members also often feel guilty because they experience emotional and physical relief after the infected has died. (as in the story of Johanna)

Feelings of guilt is also experienced by the infected as he/she feels responsible for the predicament and even embarrassment they've brought over the family. They might blame themselves for past decisions and behaviours, such as prior sexual relationships, the practice of unsaved sex, the practice of multi sexual relationships, drug abuse, et cetera. They may also experience intense feelings of guilt for having infected a partner or baby. When these feelings of guilt are not recognized for what they are, they can keep the family from making clear-headed decisions, which can in turn result in tremendous stress on the entire family.

- ***Grief***

People living with HIV/AIDS, in the long and painful course of the disease, experience one loss after another. As Jane, a 26-year-old mother of two expresses her opinion in response to my question related to grief.

> *I am not feeling sad because I am facing death … it's more than that … in actual fact, I have made peace with death – what I am "crying" about, is my dignity of which I have little left, the time with my family and friends which I have not much left of either, and the fact that I will never be able to enjoy a basic thing, like climbing a mountain or dancing … that's sad for me …*

We can therefore argue that a HIV/AIDS diagnosis may mean loss of physical appearance, loss of sexual contact, loss of health and energy, loss of friends and family and loss of personal control over ones own life and life choices. According to Menning (1980:316), "grief is a necessary and appropriate response to loss, as denial of grief may prolong the resolution process". It is therefore necessary for both the infected and affected to grief in order to ventilate all these feelings, as it is vital in controlling and maintaining a balanced stress level in the family. A denial of grief can have various stress related consequences on the family, such as, withdrawal, tension, non-communication, miscommunication, unnecessary boiled-up anger, irritation, frustration, et cetera.

- ***Fear***

In all the people I have interviewed, fear was expressed as the most common feeling experienced by all. The infected as well as those associated with them shared similar fears and anxieties. The main "themes" of fear I have clearly heard in the companion's stories were:

- Fear of the disease
- Fear of being rejected by partner, family, friends and the society
- Fear of losing control of ones life and life choices
- Fear of death
- Fear that people might find out that a family member is infected (fear of stigmatisation)
- Fear of sexuality

These feelings often lead to confusion, depression, feelings of helplessness, loneliness, negative self-esteem, negative thoughts, et cetera. If these fears are not dealt with properly, it may lead to enormous stress on the entire family.

- ***Helplessness and powerlessness***

One family member said to me:

> *Things are much better now that my uncle is admitted in this place (referring to hospice). Before we came here it was difficult – we did not know what to do. When he was angry, we would go out of the house, when he was sick, we were just praying and hoping he would be OK. It was just difficult ...*

It is not uncommon for family members to feel helpless and powerless when it comes to dealing with a terminal illness like HIV/AIDS. It's even worse and more stressful where there is no sufficient medical, family or pastoral support. It can easily result in frustration on the side of both the infected and affected.

- ***Worrying***

This is another emotional stressor in the family. Family members worry about many things such as: the sick person, about others that's effected by the illness, finances, medicine, what others will think or say when they find out about the disease. A mother expressed this feeling as she says:

> *Ek le nagte wakker en bekommer my oor honderde dinge … dit maak my moeg en gespanne …*

All these worries, no matter how "stupid" it may sound are real worries and serious concerns. If these worries are not recognised and dealt with as important matters, then it can easily result in additional and often destructive stress on the family.

- ***Despondency /discouragement***

An infected person expressed herself to me in the following way:

> *I am sick and tired of people telling me they'll pray for me … Two months ago a pastor from the Apostolic Faith mission laid hands on me and gave me "holy" water to drink… He told me that I'd be better soon. To be honest with you, I believed him… As you can see I am not better…*

Miracle answers and quick fix solutions lead to feelings of despondency and discouragement on the side of the infected and affected. This serves as a stress feeder in the family.

4.4.4 Financial stress on the family

The financial demands of HIV/AIDS treatment are extremely stressful. All of the families I have journeyed with vary between poor and middle class. Martha, a Sowetan resident and mother of seven says:

> *My eldest son is very ill. I am working as a cleaner at a primary school in Orlando West. I do not earn a lot and I am the only breadwinner. I must take him to the clinic every Thursday and that cost money (taxi fare), and at the clinic they told me that I must give him some other food – like vegetables, fruit, fish and chicken… that's more money… That helps, but we suffer… You see the other children must also get clothes and books for the school… Ai, I don't know…*

It is evident in Martha's family that caring for a person living with HIV/AIDS, is often taking its toll on the entire family. Like in Martha's case, almost all families in their desperate search for something to bring some relief to the infected person become heavily burdened financially. The result is that the family is now forced to reduce their standard of living drastically, cutting out every possible expenditure, or sometimes the most necessary and basic things such as, clothing, food, furniture, recreation and vacations. Family members are sometimes forced to take extra jobs or to work over time for an additional income. These changes and adjustments cause tremendous emotional and physical stress on the entire family.

4.4.5 Stress caused by the social network

In the introductory story told by the young Colesburg lady (Suzette), the emphasis is put on the effect of the social network on the family as she says: (Chapter 1: 2-3)

> *When I told him, he kicked me out and blamed me for everything. I then eventually went back to my hometown. When I told my family, they did not know what to do. They were more concerned about what the neighbours, their friends and the church people would say. The news eventually spread like a fire through the small town. People started to make many painful remarks, which hurt us as a family very deeply. Even the local church community started to treat our family differently. They didn't say anything, but I could feel the rejection.*

In their daily lives the family mingle with other people, such as other family (extended family), friends, neighbours or colleagues. The affected family often become affected by their social networks' reaction to them. Although HIV/AIDS contamination,.the misconceptions and myths around it, and stigmatisation, whether rational or irrational, produces enormous amount of alienation and discrimination. This causes the infected and those associated with them, to be treated and reacted differently to by their social network. The infected and his/her family are often left vulnerable to feelings of being deserted, ostracised and abandoned by those who ought to offer support, whether spiritual, emotional, moral or otherwise.

The family experiences a great deal of pressure from friends, extended family members as well as from spiritual leaders and church people as they are trying to help, in unhelpful ways by offering miracle advice, quick fixed answers and lay advice, for example, in the case where a pastor insisted that the Colesburg lady must first repent of her sin. (See chapter 1:3). The Professional Social Network (social worker, doctors, et cetera) often serves as a source of stress too. The family often feels bombarded and manipulated by the complicated knowledge communicated to them by professionals.

The social network is often a source of stress that causes the family to experience: stress, anger, isolation, aggression, powerlessness, helplessness and withdrawal from the social network and support systems. The affected family is now forced inside itself. In taking such a position, the family easily becomes a self-damaging or self-destructive system and a stressor to itself. It often leads to other problems such as:

- Secretiveness: chose to protect them against the world.

- Unwillingness to trust and confide in others.
- Enmeshment: they start relying on each other for the emotional support.
- Disengagement.
- Marital problems: such as sexual coldness, communication problems et cetera.

This can result in polarization, isolation, coldness, insensitiveness, conflict, anxiety, feelings of frustration and even betrayal towards each other.

These stresses imposed on the family relationships, create needs for support, understanding and empathy, rather than for power, manipulation or control of their feelings.

4.5 THE IMPACT OF HIV/AIDS ON INDIVIDUAL FAMILY MEMBERS

In each of the families I have interviewed and journeyed with, the presence of unique challenges to the physical, social, spiritual and emotional self of each member was presented. In this section the focus falls on the impact of HIV/AIDS on:

- the person living with HIV/AIDS,

- the parents of the infected,
- children of infected parents and
- spouse of the infected.

4.5.1 The person living with HIV/AIDS

In most individuals, the realization that one may not be the same, presents a definite crisis about identity. Most of the infected people were concerned about potential losses in all the parameters by which identity is determined, namely:

- Self-esteem
- Body image
- Prestige
- Competence
- Security and
- Relationship.

Sammy, 19 year old, Jabavu boy, who had been diagnosed with full-blown AIDS five months back, says:

> *Look at me; I am just flesh and bone... I don't feel like leaving my room... What's the use of going anywhere if you look so "stupid"? You only become the joke or #*

people feel like sorry for you all the time.

This perception of Sammy represents but one of many perceptions of which can be seen as emphasising the individuals' concept that he/she is damaged, stigmatised, "branded", or less accepted and valued by others due to how he or she looks. Although all of the wounds to the individuals' self-image are critical, the most serious consequence is when these feelings or perceptions of self are internalised, in other words when the infected individual regards him or herself as "worthless", "ugly", "no-use", "stigmatised", "unaccepted", "disabled", "powerless", "helpless", et cetera. The problem of internalisation was not uncommon in the conversations I've had with individuals.

Freedman & Combs (1996:48) put strong emphasis on the opinion concerning the problem of internalisation as they make the following profound statement with regard to the power of internalisation:

> Problems develop when people internalise conversations that strains them to a narrow description of self. These stories are experienced as oppressive because they limit the perception of available choices.

Many of the individuals admitted that this "*narrow description of self*", could lead to negative feelings such as:

- depression

- self-destructive behaviour
- self-rejection
- withdrawal
- self-blame
- self-pity
- suicidal thoughts

There is no doubt that all these negative feelings exacerbate the individuals' negative feelings about the self and so doing "feed" the problem even further.

4.5.2 The parents of infected children

Following is part of a conversation I've had with an elderly couple in Roodepoort (Johannesburg) in May 2002. The 23-year-old son of this couple had been infected with the HIV virus for almost two and a half years now. The parent's shared with me their experiences after they discovered that their son was HIV positive.

Therapist: *In the light of what you have just shared with me… I am curious to hear how "over-protectiveness" has affected your relationship as parents.*

Mother: *I am always told that I am the one that's over reacting…*

Father: *That's not true. What I mean is that you always tend to be too protective.*

Therapist: *Too protective?*

Father: *Yes. She will always do everything for Boeta… I mean it's not that he is ill… I mean he is ill, but you don't even know it… The minister was visiting one day and she told me not to tell him anything…*

Mother: (very aggressive) *Why didn't you tell him… you… why don't you stand outside and shout so that everybody could hear your son has AIDS…*

Therapist: *Is this the effect "over-protectiveness" has on your life and relationship as parents?*

Mother: (with tears in the eyes) *We … I want to do what's best for Boeta…*

Some of the most obvious elements that played out in the above conversation were common phenomena in most of the interviews I've had with other parents as well. Parents tend to be:

- Over-protective.
- Secretive about the child's condition.
- Deny or fail to deal with the conflict that arises between them.

- Displace emotions: parents often vent their anger and frustration they having towards each other to other family members.
- Disengage: one parent will deliberately avoid talking about his/her feelings in order not to hurt the others feelings.

These elements often entangle the other relationships in and outside the family. These elements were observed in most parents – not all. Some of the parents seem to manage the "problems" that may arise as a result of having to deal with an infected child more successfully than others. One of the interesting things I have noticed was the fact that parents would handle their emotional differences more successfully and sensitive in the case of an infected minor.

4.5.3 The spouse of the infected

Among other problems, sex was regarded as the most definite area of the relationship that was significantly affected. The response to my invitation: "*Tell me about the most frustrating area in your relationship as a couple*", was overwhelming. four out of the five couples referred tot heir sexual relationship. One spouse said:

> *Sex is not fun anymore. AIDS had taken the warmth out of sex. The only thing I am concentrating on during our lovemaking is the condom. I pray that it must not break*

> *or slip off. I can't remember when last I've enjoyed sex with my partner… he feels the same way… he will just not admit it. I keep myself very busy in order to forget about sex… I am scared and I feel bad about my behaviour…*

Many couples regarded sex no longer as an expression of affection and closeness, but rather as something they have to do in order to avoid guilt feelings.

Johanna said: "*Seks plaas baie druk op ons".*

In many relationships sex had become:

- A source of stress
- Leads to communication breakdown
- Leads to feelings of guilt
- Becomes perfunctory and unpleasurable
- Becomes the focus of anxiety, anger, and blaming or depressed withdrawal.

There is therefore a need for the development of new sexual identities in each partner where sexuality is separated from sex. It is possible to be sexual without sex. The therapist needs to guide them to see sex as a critical part of their relationships, but not the relationship in itself.

4.6 BEREAVEMENT IN THE FAMILY

At this moment I would like to share the way I have personally experienced the face of death as I was standing with family members next to the deathbed of an 8-year-old boy who was dying of AIDS.

At 10h20, Thursday morning, 20 June 2002, I got a phone call from Edward, a family member I have journeyed with since April this year. His son was dying and he wanted me to be there. It took me less than 40 minutes to get to Baragwanath hospital. About 7-8 people were standing around the little boy's bed. From eleven in the morning I had been keeping watch, stage by stage. The boy was just lying there, sweating and without speaking or opening his eyes… All of a sudden he was uttering a long, shrill wail. He was coughing and crying together. He was struggling to breathe and in the process tossing his head wildly to and fro. From behind the close eyes, big tears welled up and running uncontrolled down his sunken cheeks.

I suddenly, for the first time since I have entered the ward, looked at the family. A gust of sobs swept through the room, family members were crying, others were praying aloud and yet others were just mechanically standing there.

It was an especially difficult period to see this boy, so young of age, spiral downward to inevitable death, but it was even worst to see how family *members were suffering as they were watching this tragedy. The various emotions: fear, anxiety, helplessness, powerlessness, sadness, pain and fatigue could clearly be read on the faces of family members. He died shortly after one o'clock.*

I walked an intense road with the family, conducted the funeral and journeyed with them for weeks after the funeral.

It was in that experience that I have realized to what extend bereavement can affect the physical and emotional health of those who cared for the infected. In my journey with them, I often heard them saying things like: "I *feel very tired*", "*I don't feel like getting up in the morning*", "*I still cannot belief he is dead*", et cetera. These expressions are indicative of the intense emptiness, loss of control, powerlessness experienced by family members. I have also noticed how drastically an HIV/AIDS-related death can introduce changes in family structures, to an extent that family members can be torn apart.

I agree with Raphael (1984:54) as he writes:

> The family unit as it was before dies, and a new family system must be constituted. The death will be a crisis for the family unit as well as for each individual member and each component subsystem.

It can therefore be argued that specific bereavement needs develop from within the bereaved family unit. These needs, if not attended to, can lead to many other negative and destructive consequences. Louw (1989:184) categorises these needs in to five phases, namely:

- ***Die verwarde fase***

During this phase everything feels unreal and the family experiences intense emptiness. Disorientation is another sign of this phase. Basic things like normal daily tasks become extremely difficult and complex. Family members also find it difficult to verbalize feelings to one another. Members do not know how to ventilate feelings of hurt and confusion to each other. They are very sensitive to each other's feelings. Members need to be helped to see the loss as their collective loss and the responsibility to work through it, as their collective responsibility.

- ***Die soekende fase***

During this phase family members become pre-occupied with the bereaved. They "include" the dead person in all their *doings and thinking*. Family members develop intense feelings of "vermisting".
As one family member said to me:

> *I cannot stop thinking of my little brother. At the table (at meals), in Church, at work, even in my sleep (dreams)...*

Family members need to be guided to a "place" where they can live with the person that's no longer there physically.

- ***Vormingsfase***

In this phase the family is challenged to make new (alternative) adjustments – to take on new roles.

- ***Ordeningsfase***

The family members are encouraged to work together towards formulating new goals, new challenges, new family interests – in order to live more purposeful as a family. They are encouraged to find an appropriate place for the dead member in their emotional lives – a place that will enable them to go on living effectively.

- ***Die kontinueringsfase***

In this phase family members are encouraged to regard each other as critical support in the ongoing restructuring and re-authoring of the family unit and each other.

4.7 IN CONCLUSION

In this chapter I have listened to and interacted with real life stories pertaining to various impacts HIV/AIDS has on the family. To be more specific, I have examined, explored the impact of HIV/AIDS on the individual, the family unit, significant others and the emotional reaction and stresses on the family relationships.

From my interaction with various stories, it became clear that HIV/AIDS affects the ego, sexual identity, self-image, role fulfilment, emotional, physical and the marital relationship as well the emotional normal function of the family.

HIV/AIDS can therefore be understood as an integral issue, affecting people individually and corporately. The result is therefore that families often find themselves in a situation that is difficult to cope with as individuals, and as members of a social network.

HIV/AIDS can be regarded as a kind of "nameless" and often "silent" state where both the infected and affected experience what they want life to be and what life is, as in conflict, or differently put, their past, present and future stories refuse to interact with each other. Muller (1999:7) describes this "hostile" story interaction as "a cul-de-sac story – a story that refuses to take on a form which would link to the future".

The whole HIV/AIDS experience therefore attests to the need for counselling or therapy where:

- the companions are helped to tell their story of need as fully and broadly as possible,
- the companion(s) are invited to tell the history of the story of need,
- the companions are invited to evaluate the effects of the depressive story on them,
- the therapist together with the companion(s) are invited to discover an alternative future story,
- the distorted and oppressive story is re-authored into a new story,
- the companion(s) is invited to imagine a better future.

(Muller 1999:84-5)

In the following chapter, the narrative paradigm in pastoral family therapy is described and discussed as framework for doing therapy with both the infected and affected.

CHAPTER 5

THE NARRATIVE PAPRADIGM IN PASTORAL FAMILY THERAPY

> *"In initiating conversations we may need to modify the way in which we do the leading or present the message" (Erickson 1998:155)*

5.1 INTRODUCTION

Erickson (1998:155) emphasises the need for a more pragmatic and anti-theoretical approach in therapy as he writes: "In initiating conversations we may need to modify the way in which we do the leading or present the message...". The shift in family therapy from a cybernetic metaphor to a narrative metaphor is described by Freedman & Combs (1996:1-2) as that which:

> leads us to think about people's lives as stories and to work with them to experience their life stories in ways that are meaningful and fulfilling. ...the metaphors that we use influence what we look, listen, and feel for...

This new understanding of viewing and doing therapy leads us to think differently about therapy, about those coming to us for therapy, and about our roles as therapists.

In this chapter I pursue how this different way of thinking, viewing and doing has developed historically, theoretically and practically into an approach that has consequently opened up space for a different way of working therapeutically. I will begin by tracing the gradual development from systems to narrative in the field of family therapy. It is perhaps appropriate to start with a brief historical view of family therapy before venturing into a more detailed exploration of pastoral narrative therapy.

The main portion of this chapter will primarily, but not exclusively focus on the narrative ways of working that have risen among therapists, who were inspired by the pioneering efforts of Freedman & Combs (1996); White and Epston (1990); Muller (1999, 1996); as well as other authors sharing the same paradigm-thinking.

5.2 BRIEF HISTORY OF FAMILY THERAPY

5.2.1 A development from linear to circular thinking

Throughout the first few years of family therapy, the dominant trend was cybernetic theory. The focus was exclusively on the individual with the "problem". The reason for this one-sided approach is described (and "justified") by two thought of schools, as follows:

> Freudians excluded the real family in order to uncover the unconscious, introjected family; Rogerians kept the family away in order to provide the unconditional positive regard they thought necessary to help clients rediscover their own inner promptings...
>
> (Nichols & Schwartz 1991:65)

This quotation emphasises the fact that therapy was deeply influenced by the belief in **linear causality** theories based on individual motivated principles.

The focus was on the:

- Confidentiality relationship between therapist and individual.
- Problem **in** the individual, and
- Inner promptings of the individual, rather than on family dynamics.

This parochial view exposes the individual as the bearer of the problematic behaviour – the behaviour of one person was therefore seen as the cause of other problems that might have occurred. This form of therapy, I would say, is bias in nature and opens up space for *naming*, *blaming* and *labelling* of the individual. Such an approach can have very negative and lasting emotional effects on the person, but also on the entire family. Internalisation is an automatic consequence of this approach.

In the 50's, a new perspective was introduced. A shift from **linear to circular causality** took place. Goldenberg & Goldenberg (1991) quoted by Muller (1996:141) interpret this shift as follows:

> The emphasis here is on forces moving in many directions simultaneously, not simply a single event caused by a previous one.

Muller (1996:141) reinforces the above statement as he elaborates on Goldberg & Goldberg (1991) understanding of the circular shift as he writes:

> In 'n gesin word al die ander lede geraak deur die verandering in een lid. Dit het dan 'n eggo-effek (*reverberating*) wat weer terugkom na die een lid en wat hom/haar dan weer beinvloed, en so gaan dit voort in 'n voortgaande reeks van terugvoerkringlope of kettings van beinvloeding.

In this shift the family is understood as a functioning unit in which all members interact with one another and consequently affect one another. "The behaviour of each person of the family directly affects the behaviour of every other member" (L'Abate, Ganabl and Hamsen 1986:10). This paradigm emphasizes the fact that the family is a unit of interacting personalities and that any disruption or dysfunction in any of these personalities, in their relationships, or their interaction in the family unit will be disrupted and felt in all other aspects of the unit. The focus is now shifted from the individual to the family. The family is seen as the "patient" or the "problem". The task of the therapist was therefore to identify the cause of any disruption or dysfunction in the family unit and thereafter to empower the members to deal with it accordingly. The obvious weakness of Erickson's supported approach, is criticized by Nichols & Schwartz (1991:66) as they write: "But Erickson's mesmerizing artistry also promoted a tradition of the quick fix, done to rather that done with families". Another weakness of this approach was the fact that some family therapy models within this metaphor involved specifying truths about families, others specified functional connections between families and problems, and yet others merely stated the necessity of change along with what therapists had to do for change to happen. The family was now viewed as the context in which problems are played out. The family was the focus of treatment or, as I already mentioned, the "problem".

In the 60's and 70's the focus shifted entirely to the therapist as the expert, the one with the power to fix from outside. Freedman & Combs (1996:3) sums up this position as follows:

> Therapists focussed on how families could become stuck in repetitive loops of unfulfilling behaviour or in hierarchical structures that were improperly balanced, and on what therapists could do to interrupt those patterns and guide families into a healthy rather than an unhealthy stability.

In the early to mid-1980's, yet another new perspective was introduced that alerted therapists to the idea that perhaps all that they had was a perspective. The second-order cybernetics was introduced. Both the first- and second-order cybernetics will now be described in more detail.

5.2.2 First-Order Cybernetic Model

It is perhaps important at this stage to unpack or perhaps more correctly put, “unmask” the word “cybernetic”, in order not to only highlight its underlying “power”, but also to “expose” some of the obscures when it is used to guide ones thinking and perceptions.

Freedman & Combs (1996:3) coined the word “*cybernetics*” to refer to “an emerging body of knowledge about structure and flow in information-processing systems”. The word derives from the Greek word “*kubernetes*”, which according to the Oxford Advanced Learners Dictionary signifies: “power”, “governor” and “controller”.

It can therefore be argued that, according to the above description, the word “cybernetics” can be understood as synonymous with phrases such as: “a science of guidance”; “error correction”; “to manipulate”; and “power abuse”.

According to Freedman & Combs (1996:3), in this paradigm, “we tend to think of the help we offered as being in controlling things so that a specific goal was reached”.

It can therefore be argued that the dominant trend in taking this position as therapist, is to function as an observing controller. The first-order cybernetic paradigm invites therapists to view themselves as:

- in power/authority
- in control
- the problem fixer
- the miracle worker
- the answer giver
- the omni-scientist (the one who knows everything)
- the expert
- the subtle imposer (or manipulator)
- diagnostician

The therapist functioning within this framework, sees him or herself as the one who needs to take the responsibility for developing interventions or strategies to interrupt in order to correct or change any dysfunction or misbalance that might occur in the family unit or the individual. The therapist believes he or she has the absolute answer or specifying truths about the family's situation, that he or she knows the specified functional connections between families and their problems, and that he/she has the ability to make the necessary changes to happen where needed.

This paradigm invites the therapist to view families and individuals who come for therapy as machines that need to be fixed. The therapist set the goals, the rules, direct the movements and predict the outcomes of any given situation. The therapist is seen as impacting on the "object". In other words, the family or individual coming for therapy is seen as the object whilst the therapist views him or herself as the agent. His/her task is to treat dysfunction as the focus of therapy.

The one seeking help is automatically degraded into:

- the object
- the not-knower
- the one that needs to be fixed
- the problem or
- the dysfunctional one.

This model or paradigm is inviting people to behave in even more mechanistically controlling ways towards themselves, and the process gives the therapist too much credit for changes that occurred, while the people seeking help easily experiencing themselves as passive puppets of their controlling masters and give themselves too little credit for changes they might have initiated.

This model or paradigm imposes many negative effects on both the therapist, the one seeking therapy and therapy. Following is but a few of the numerous negative effects that might spring from this shift:

- the one seeking therapy ceases to take responsibility for his/her own changes/growth,
- becomes easily dependent on the therapist and therapy for their normal function (becomes "addicted" to therapy),
- the therapist can be burdened with the unattainable quest to be the one with all the secrets, miracle solutions and quick fixed answers to peoples problems (pressure to perform),
- the therapist can easily take too much responsibility for what's wrong in other peoples lives. The therapist can easily internalise therapeutic mistakes and "failures" (e.g. feelings of inadequacy, et cetera),
- the therapist can "fail" to maintain a position of subjective integrity,
- the therapeutic process can be robbed from its integrity.

It is precisely for all these reasons (and many more) that there has been a move-away from this metaphor, which has been at the heart of family therapy theory for several decades as theoretical basis for therapy.

5.2.3 Second-order Cybernetic Model

The shift to second-order cybernetics was clearly an indication that people were beginning to think differently about systems. Hoffman (1988:112) suggests in her article: *A constructivist position for family therapy*, that there is a definite need for, as she calls it, "a less control-orientated model, a model that does not place the therapist outside of or above, the family".

Freedman & Combs (1996:5) write about this new way of thinking as follows:

> It developed as people began to realize that the therapists couldn't really stand outside of family systems to make "objective" assessments and adjustments. A therapist was, like it or not, part of the very system undergoing therapy, and therefore incapable of detached objectivity.

This new realization brought a few main implications with current importance, namely:

- *A shift away from any kind of causality.*
- *A move away from positive explanation towards negative explanation.*
- *A shift from a theory of restraints.*
- *A shift from privileging the therapist's point of view.*
- *A move towards acknowledging the importance of the experience of the one seeking therapy (companion), based on his/her own point of view.*
- *A move towards acknowledging the partnership between therapist and the companion(s).*
- *The recognition that there are not absolute truths.*

This realization has implications for the therapist, companion(s) and the therapy process.

Firstly, **the therapist** is:

- partly part of the very system undergoing therapy;
- less in a controlling or powerful position;
- not the one who knows everything (but is still in a "more" or "better" knowing-position);
- a co-partner with the family, not a companion (the therapist is still the slightly more superior one).

Secondly, **the one seeking therapy** is:

- a co-worker with slightly less power than the therapist;
- part of a "co evolutionary ecosystem located in evolutionary time space" (Freedman & Combs 1996:5);
- connected in ongoing relationships (not seen as entirely the problem);
- not entirely on the mercy of the therapist;
- given some credit for changes that might occur.

Thirdly, **the therapy** itself:

- is a process where both therapist and the one seeking therapy are involved;
- consist of less power-language – words like, "co evolution" and "co creation" became more part of therapy;
- undergo a "face-lift", "instead of looking for patterns of behaviour in families, they were looking for pattern of meaning" (Freedman & Combs 1996:6)
- is less concerned with problems naming and labelling – moved to identifying a premise that was shaping the meaning of family members;
- is shaped by circular questions which make it possible *to get* rather than *to give* information from those seeking therapy.

It can therefore be argued that in the second-order cybernetic model, there is a deliberate and partially move-away from an object-subject-position, a give-and-get situation, or a position where power is imposed. This becomes evident in the words of the second-order cybernetics therapist, Erickson (1980:223) as he points out that:

> What is needed, is the development of a therapeutic situation permitting the patient to use his [her] own understanding, his [her] own emotions in the way that best fits in his [her] scheme of life.

The second-order cybernetics model is most definitely opening up space for story development, but at the same time, giving enough power to the therapist to artificially manipulate and, in a very subtle way articulate meaning for the "character's" story. This means that the therapist is still yielding a significant amount of control over the "characters" and their stories, which in turn robs the story as well as therapy from its integrity and degrades the "characters" into what I call "empowered" objects, in other words, the power of hierarchy between therapist and those seeking therapy is just softened or flattened – not illuminated. There seems to be still not enough room for non-therapists voices, as well as inputs and ideas in second-order conversations. The therapists' task is still too much focussed on a subtle proselytising of the co-worker with his or her own beliefs and understandings.

5.2.4 The Narrative Approach in Family Therapy

It would be utterly untruthful and dishonest not to acknowledge and recognise the importance of the second-order metaphor in the whole narrative debate. I think it is appropriate and necessary not only to recognise the importance of the second-order metaphor, but also to acknowledge that using a narrative metaphor allows for an understanding almost similar to a theory of second-order cybernetics, but with some clear differences. Every metaphor presents different implications for how change is to occur. In both instances we deal with experiences of people that often do not fit or make sense of any given experience or story. In dealing with that, *which do not fit*, is perhaps where the obvious difference come in between these two approaches. With the second-order metaphor, interventions are directed towards highlighting and dealing with "**information**" or "**data**" which *does not fit* whilst with the narrative frame of working, the therapist looks for **experiences** that are not currently being storied, which do not fit into the dominant narrative or story – people are then invited to develop an alternative story around these experiences. It is not the information or data about "*that which does not fit*" that is important (as in the case of the second-order cybernetics), but rather the potential meaningfulness of the **experience** to the alternative story.

Freedman & Combs (1996:1) capture the message that I am trying to convey, in very straightforward language as they write:

> Using the narrative metaphor leads us to think about people's lives as stories and to work with them to experience their life stories in ways that are meaningful and fulfilling.

Muller (1999:2) is expressing the same reservation as Freedman & Combs as he writes: "If one works from a narrative perspective, you increasingly realize that you are totally a part of that which you are seeking to offer".

The narrative approach can therefore be argued, is less concerned with clever strategies, hierarchy or techniques that are aimed to influence people to do things that would begin to move their lives in new directions (as in the case of both the first- and second-order cybernetic models). It rather invites and encourages the therapist to no longer speed energy on trying to solve or correct problems, but instead, to become interested in working **with** people to bring forth stories that did not support or sustain the very same problems that we as therapists so desperately want to solve, correct or fix. I agree with Freedman & Combs (1996:16) as they point out:

> that, as people began to inhabit and live out these alternative stories, the result went beyond solving problems. Within the new stories, people could live out *new self-images, new possibilities*: for relationship, and *new futures*. (Italics mine)

Other writers whose thinking are in line with Muller (1999) and Freedman & Combs (1996), are Valeric Edden (1991:60), who recognises that "with stories we can more easily make sense of the world and place I it"; and also Tolaas (1990:v), who argues that "telling stories is essential in bringing back hope". Tribe (1984:1) captures the power of stories as he writes: "Even sad stories are able to generate new beginnings".

The place given to stories by these authors, in a therapeutic context, most definitely opens up a new world full of surprises for both the therapist and those coming for therapy. We can therefore come to the understanding that working narratively is valuable and almost unthinkable in all pastoral therapeutic situations.

We can therefore come to a preliminary conclusion that attending to the narratives of people can have deep implications for the way in which the therapist elicits and interact with those stories. It is therefore of critical importance to understand the narrative approach as more than just:

- "the art of telling stories" (Muller 1999:1);
- "telling and listening to stories" (Robertson 1990:35);
- a scientific approach who needs "scholars whose task it would be to analyse the stories according to scientific process" (Muller 1999:1);
- "simply a further evolution of systems theory" (Freedman & Combs 1996:14);
- the opinion that social constructivism and constructionism are the same;
- a technique, strategy, structure or a fixed model.

The following conclusions can therefore be drawn about the Narrative paradigm in Family therapy: (The therapist needs to be empowered by this framework)

- The focus is on effects instead of causes.
- The narrative paradigm uses experience as primary focus, rather than information.
- It shifts from people's relationships as the object of therapy to their stories about their relationships as the object of therapy.
- It regards experience as larger than the problem-filled stories.

- The emphasis is on how best the companion can intervene and make meaning out of his/her problem-saturated story, rather than how best the therapist can inject change, correct or fix it.

White & Epston (1990:10) summarize this companion-orientated (persons' task) responsibility in the Narrative paradigm as follows:

> In striving to make sense of life, **persons** (companions) face the **task** of arranging **their** experiences of events in sequences across time in such a way as to arrive at a coherent account of **themselves** and the world around **them**… (Emphasis mine)

After having discussed the "secular" importance of stories, it is possible to ask "**what is the place of stories in pastoral therapy where pastoral therapy (counselling) is seen as an activity of the church and its ministry**". Another question unanswered so far is why story, or narrative, is an appropriate theological medium in which to speak of experience.

Muller (1996:45) gives us a basic framework for exploring and interacting with the above questions as he writes:

> Voordat die verskillende opsies van nader bekyk word, stel ek eers 'n basiese teologiese uitgangspunt, naamlik die betrokkenheid van God by die mens… Hierdie betrokkenheid verwys na die verhoudinge tussen al die partye wat in 'n pastorale situasie ter sprake is: nie net tussen pastor en lidmaat nie, maar ook tussen

> God en mens. Die uitgangspunt is dat God nooit net 'n toeskouer is nie, maar 'n deelnemer aan die pastorale gebeure.

In the next section, attention will be given to the development of hermeneutically orientated models and practices, which contributed to a "model" of understanding and discerning, what I would call, the "**God-people-therapy** relationship-approach". This approach is embraced in the **Pastoral perspective in narrative therapy**.

5.3 A PASTORAL PERSPECTIVE IN NARRATIVE THERAPY

I have a strong sense that pastoral care is being carried out within the context of being able to listen to ones own life. As I was listening to the many stories of people being bombarded by the bad news of HIV/AIDS, I suddenly came to the realization that one could not escape the reality that our theology and pastoral approaches sometimes contribute to the relegating of God to somewhere far away from our experiences. In this section I will therefore look at the various approaches, which contributed to a new understanding of the phrase: "*GOD WITH US*".

5.3.1 Eco-systemic influence on the pastorate

The quotation below, contains words that show an obvious and strong leaning towards systems influence in pastorate. I would like to look critically at the implication of this quotation in the light of our understanding of *pastorate*. Heitink (1984:75) describes pastorate as follows:

> Als **hulpverlening**; dat een pastor een **helpende** relatie aangaan met mensen om – in het licht van het evangelie en in verbondenheid van Christus – met hen een weg te zoeken in geloof – en lewensvragen. (Emphasis mine)

I personally feel very uncomfortable interpreting pastorate as "*hulpverlening*". No single word captures more accurately, or expresses more eloquently the "impotent" influence of the first-order cybernetic metaphor on pastorate than the word "**hulpverlening**". The word "hulpverlening" can easily be coined and associated with the following first-order cybernetic impressions and images, that:

- "I know better or more"
- "I am the one in charge"
- "I need to give guidance"
- "I know the answers to your problem"
- "I have the knowledge or training that can help you", et cetera.

I have already begun to discuss the effects of both first- and second-order cybernetics on the therapist, those coming for therapy, as well as on the therapeutic process.

In the interviews I've had with pastors (see Chapter 2) it became evident that yet, inspite of the many obvious negative consequences involved, the "*hulpverlening*" understanding of pastorate, is still very much an actuality in pastoral counselling spheres. I need to admit, that despite the often stuckness in this therapy tradition, there is an ongoing obvious and almost aggressive progression towards a new and liberating way of doing and thinking about therapy.

Mills & Sprenkle (1995:368) describe the paradigm and the influence it had and still has on the pastorate as follows:

> This was [and I would say, to an extend still is] a technical paradigm, and families [and individuals] were assumed to follow a discernible and disruptible pattern of self-correction, *which the therapist, as an outside observer, could adjust through skilful and informed intervention.* (Italics mine)

The shift from linear to circular causality had, without doubt, a revolutionary implication on the theoretical and practical interpretation on pastoral therapy. Pastoral therapy became an opportunity, not to eradicate the problems, but to help members in their system (the family, church or society), to change their relationships through dialogue.

In this shift, people were seen as being able to organize their own problem-saturated experiences, not so much through the clever intervention of the pastoral therapist, but rather through "... natural consequences of dialogue" (Anderson 1993:324).

Charles Gerkin's (1997:37) description of Practical theology as framework for pastoral care beautifully sums up the focus of this paradigm as he writes:

> Pastoral care in its larger meaning, however, involves the pastor in giving caring attention to concerns that reach beyond the individual to the community of Christians and the larger society.

It can therefore be argued that pastoral care had moved away from an individual centred approach, or perhaps more contextual, and communal approach, or perhaps more correctly put, it is a new way of understanding the process of "facilitating transformation of life in all its dimensions in accordance with the Christian gospel" (Gerkin 1991:64) (Italics mine). Muller (1996:7) puts even more skin to the bone as he writes: "Dit gaan veel eerder oor 'n nuwe verstaan van verstaan". This new interpretation of understanding gave birth to a new paradigm in pastoral ministry, called **Eco-Hermeneutical pastorate**.

5.3.2 Eco-Hermeneutical pastorate

- ***Hermeneutics***

According to Osmer (1990:223):

The term *hermeneutics* derived from Greek, and was originally connected to Hermes, the messenger of the gods, whose task it was to make the messages of the gods intelligible to human beings.

This interpretation suggests an understanding that, in my opinion, is obviously improperly balanced. In this view it is presupposed and gives the impression that the communicator of the message is separate from those receiving the message. The word "gods", "message", "messenger" and "intelligible" signify:

- unhealthy stability,
- object-subject relationship,
- hierarchial structure,
- imposed, inflicted or prescriptive communication,
- superiority and inferiority status,
- a tendency to objectify pathology.

The implication of this understanding in pastoral work, is the idea that God has send the pastor in God's authority to provide help to the "helpless" or those in "crisis". I see such an understanding of communicating a message

(God's message) whether through preaching, writing, reading, counselling or any other form, as oppressive, un-pastoral, un-theological and therefore inappropriate for therapy. It invites and gives the therapist "permission" to treat people as objects, it dehumanises the therapeutic process, and it robs God's story, of which we as therapists are messengers, from its integrity. It puts the therapist in a position of transcendence, an "above"-position and those coming for therapy in an immanent or "below"-position.

Firet (1986:95) sums up the proper and improper understanding of what hermeneutics is as follows:

> Pastoral role-fulfilment is hermeneutic or it is not pastoral role-fulfilment, not intermediary of Gods' coming [or message I would say].

Analogous to the original understanding, in the earlier Christian Church, hermeneutics was seen as the theory of interpretation, aiming at the discovery of rules that would yield a **correct** sense and interpretation of Biblical texts. Since the Enlightenment, the meaning of this concept changed, reflected in the work of such philosophers as Schleiermachor (1974), Dilthey (1914), and Gadamer (1983). Rather than trying to discover interpretive rules, these men initiated an approach that analysed the process of interpretation and understanding itself. Hermeneutics thus shifted its focus from what use to be a very parochial or, narrow, and I would argue, a non-narrative interpretation to a process of understanding. It therefore changed from:

- the correct sense of interpretation to an interpretation of understanding,
- the interpretation of facts to the understanding of experiences,
- the interpretation of exclusive personal experience to an interpretation of an inclusive contextual experiences,
- linear understanding to circular understanding,
- a more or better understanding to a new or different understanding.

This encounter is described by Gerkin,(1991:19) as a "*fusion of horizons*". This practice, "*fusion of horizons*", can therefore be understood as an intense relationship between God, the Word, individuals and their contexts. This understanding opened up space for the Eco-hermeneutical approach. This approach is described by Muller (1991:92) as: "die verstaan van die mens en die verstaan van God se wil vir die mens in 'n spesifieke situasie".

▪ *Eco-hermeneutics*

As seen in the above quotation of Muller, the Eco-hermeneutical approach focuses on a holistic understanding. Van Den Berg (1995:53) describes this approach as follows:

> Hierdie perspektief kyk holisties na die mens, vanuit 'n bree perspektief, die totale menslike wereld of omgewing. Maar die perspektief kyk ook na die verstaan van God se wil vanuit die skrif asook na die wil van God vir die mens binne sy probleem situasie.

This approach has many and vital advantages for pastoral ministry. Following are but a few of the many advantages:

- It resolves the tension that exists in "client-centred" approaches (as seen in first- and second-order cybernetics).
- It makes it possible to see both the individual and the Word of God as stories that interact with each other.
- The relationship between role players is clarified without overemphasizing a specific one.
- The eco-hermeneutical approach gives the companions in dialogue a fundamental uniqueness as interpreters of their own live experiences.
- Both the therapist and the one seeking therapy become the channel through which God influence the pastoral encounter. Therefore, the story of both partners can be changed and enriched by the encounter they both experience with God.

The Eco-hermeneutical approach therefore does not only provide the therapist with insight in the process of therapy, but with fresh understanding of how they do and think about therapy. It provides the therapist with a framework for an approach and process that involves *God*, *people* and their *contexts*.

This approach sees the interpretation of understanding as a central phenomenon in how individuals perceive reality. Rather than referring to an inner homeostasis that should be preserved or restored, the individual interpretation, appraisal, or attribution of meaning is seen as a key concept in this approach. I do not seek to exclusively endorse any of these sub-approaches in this section as superior to any other, but it seems to be more useful to regard the eco-hermeneutical approach as one in which the most fundamental questions of faith and meaning come to the fore. Notwithstanding this very profitable and valuable input, we need to realize that Narrative pastorate is not a further evolution of the eco-hermeneutical paradigm, but rather a new paradigm influenced by the eco-hermeneutical paradigm in pastoral family therapy.

- ***Eco-hermeneutical pastorate***

Muller (1996:15) is of the opinion that:

> Pastoraat wat vanuit 'n eko-hermeneutiese paradigma gedoen word, mond uit in 'n pastoraat van betrokkenheid by die totale narratiewe werklikheid wat ter sprake is.

With Muller's view in mind, it can be argued that pastorate can never be done on a subjectivism – objectivism scale, but rather in a process through which all role players are taking equal responsibility for dealing with a shared reality, shared meaning, and shared purpose. This process can never be reduced to a relational vacuum. The pastor is to provide the ultimate facilitative conditions for the companions to interact with his/her own story, with one another, with

God, and their context in order to enable them to become equal "share holders" in their search for meaning. The inter-relational dynamics in Eco-hermeneutical pastorate is beautifully summed up in the words of Muller (1996:14) as he writes:

> ... die eko-hermeneutiese paradigma val op die verstaan van die geheel en die ontdek van die betekenis van die geheel-konsep binne verskeie kontekste.

This brings us to a much broader understanding of what *pastorate* is. It is perhaps; at this point appropriate to "investigate" this broader understanding of *pastorate* as well as its implications on the position of the pastor as narrative therapist.

5.4 NARRATIVE PASTORATE AND THE POSITION OF THE PASTOR

5.4.1 Narrative pastorate

Coetzee (1993:8) gives a narrative identity to pastorate as he writes: "dit gaan om die verstaan van die mens en die verstaan van God se bedoeling met die mens".

Bon-Storm (1989:91) enforces Coetzee's understanding of narrative pastorate and puts emphasis on the fact that pastorate is not an exclusive, but rather an inclusive and holistic approach as she writes:

> ... geen doel in zichself. Pastoraal is een middle om te kom tot een leven al gelovige, de voeten stewig in die grond van de **menselijke ervaringswereld** en in die grond van het **geloof** in en de hoop in en hoop op **Gods** trouw en passie voer **mens** en **wereld**. (Emphasis: mine)

With this understanding in mind, we can come to the "conclusion" that the task of the narrative therapist is to help the "troubled" companion(s) to understand and interpret God in the light of his/her experience and, conversely, to understand and interpret the "troubled" companion(s) and his or her experience in terms of God's involvement with that experience. Daniel Louw (1994:77) puts this interaction between experiences beautifully as he writes:

> The patient's [companion's] story must be put in touch with God's story and vice versa... where these two stories converge and the patient [companion] discover God's fulfilled promises, hope emerges.

Narrative pastorate should therefore not exclusively be understood as a means of communication and active listening, but more so as the quest for meaning. Van Den berg (1995:10) points out: "In singewing gaan dit om verstaan, die verstaan van bepaalde mense in die betekenis van God se wil vir hulle". Josef Mayer-Scheu (1997:24) sees the pastoral therapists' role here as "to sustain people when they are grappling with meaning of life".

Narrative pastorate could therefore be described as the context in which the companion(s), the context, the pastor and God constantly and continuously interact with each other. In this interaction, people become aware of their own limitations, but at the same time becoming aware of their great unlimited strengths in God. In this context, the pastor is more than just a provider of answers to questions, he or she functions as instruments in God's divine process of healing, wholeness and reconciliation. Fuehier (1960:40) brings this dimension of faith core to the fore when he says, "that pastoral care comprises no compulsion to convert". On the basis of Fuehier's expression, it can therefore be argued that what pastors do in pastoral care is of minor importance, compared to what happens to the "troubled" companion in the meeting between pastor and "troubled" person in the presence of God.

The crisis arising from HIV/AIDS gives rise to many distorted images, problem-saturated stories and oppressive experiences of *self, others* and *God*. The idea with this study is to embark on a possible way of bringing these images, stories and experiences in perspective with God's story within a narrative-pastoral therapeutic situation. An excellent way of putting this is contained in the words of Coetzee (1993:8) as he writes: "om die mens sy eie lewensverhaal te laat verstaan in die lig van God se verhaal".

5.4.2 The position of the Narrative pastoral therapist

As already mentioned in Chapter 1:6 (1.2.1), as narrative therapist I position myself within the social constructionist paradigm. This paradigm is different from the constructivist approaches, which seems to lead to an attitude of pure utility. Following is a further elaboration on this position.

The major implication and therapeutic challenge of aligning oneself with this paradigm is captured in the words of Erickson (1998:155) as he writes:

> In initiating conversations with a deconstructionist, we may need to modify the way in which we do the leading or present the message. This may mean that a more narrative presentation, not in the hermeneutical or heuristic but in the communicational sense of narrative, will have to be the beginning of the conversation.

At this point I would like to share my own personal story as “developing” narrative therapist.

The position outlined in above quotation, (and in Chapter 1) was not adopted by me without its problems. As a new therapist, I almost felt like a magician – someone who was supposed to have the answers to all questions and solutions to all problems. Even before I offered for the full-time ministry, I felt this strong calling into the counselling ministry. I worked hard and struggled much in my desperate attempt to understand and accept certain counselling *techniques and strategies. Inspite of my endless efforts of attending workshops, counselling courses and my formal training, I could just not manage to make it my own. I wanted to be more than a good counsellor; I wanted to be an expert in my field.*

I now realise how much I had been a victim of the culturally dominant voices in the Christian tradition. My role was not only influenced, but also determined by this dominant culture. As a minister I was made to belief and understand my role to be that of:

- *A worship leader*
- *The messenger*
- *The church manager*
- *The spiritual doctor*
- *The teacher*
- *The shepherd*
- *The ordained*
- *The theologian.*

These roles "forced" on me an identity, which I believe gave me a role and function that seemed to be more special, more important than others, different from others, more knowledgeable and superior. It created in me, as therapist, a tendency, or the will to dominate, to be in control – not only of myself, but also of others and their problems. Even worst, I though people wanted me to *be their "expert". For many years I have happily bought into this system and culture which was "created" for me by society and specially the church and Christian community.*

These dominant cultures made it difficult for me to make a paradigm shift. In 2000, I was introduced to narrative therapy as a Masters' student. At first I struggled to come to grips with this overly "stupid" and "simple" method. I struggled with finding my personal identity as therapist and kept finding myself pulled into the old mould of doing and thinking about therapy (in the way I was conditioned).

As my studies were progressing, I began to find myself more and more attracted to the narrative ideas and practices. In September 2000, I had the privilege to attend an intensive workshop on Narrative therapy, conducted by Jill and Gene Freedman (Freedman & Combs). After he five days of workshopping, practicing and engaging in Narrative therapy, I became totally converted to this new and exciting paradigm.

It's a wonderful relief not having to be an answer giver or a problem solver. I found the unattainable quest and overwhelming burden of the "expert"-position to be lifted. It's an absolute liberating feeling to know I know not more than those coming to me for therapy and it is actually a great feeling being able to collaborate with them as a team, as partners or companions, rather than feeling alone and responsible for the process of therapy. This approach *developed in me a sense of respect, not only for those coming to me for therapy, but also for the process and for myself. It taught me that "problems are problems and people are people" (Freedman & Combs 1996:2).*

The holding-on to this story helped and is still helping me in a considerable and continuous way with my own Narrative-identity-formation. It helped me ask questions, which constantly reminds me "where I am coming from", "who I am", "where I am" and "where I am going to". These questions remind me of the fact that I can never be involved in the story of the other without being involved in my own story. I whole-heartedly agree with Muller (2000:17), that the narrative therapist "kan hom nie losmaak van sy eie storie nie". This "self-story-consciousness", as I would like to call it, has the power to empower the therapist to self-understanding. It also becomes a platform on which one beginning to deal with ones own prejudices, bias, perceptions, stereotypical ideas and assumptions, such as:

- "ministers are the boss of the church"
- "pastors know more about peoples' pain"
- "theological trained people are more knowledgeable"
- "people coming for therapy (counselling) are problems"
- "a minister that does not know, is inadequate"
- "pastors are "talkers" (preachers)"
- "pastors are send by God to solve human problems"

Muller (1999:21) is of the opinion that this process of deconstruction naturally begins when we “bring our stories of skeletons... out of the cupboard”. He proceeds by saying:

> We need to be honest with ourselves and, as far as possible, honest with others... Such an awareness includes an acknowledgement to yourself...

Taking such a position, the therapist allows him or herself not to function in isolation, but allows him or herself to be actively involved in the others’ stories, not as the expert, but as a companion. This brings us to another important point make by Muller (199:66) as he writes: “The story of the self cannot be told without the stories of the selves of the rest”.

This brings us to the role of the narrative therapist as described by Pienaar (1996 – 194/5). I fully agree with Pienaar as he describes the role of the therapist in a pastorate of narrative involvement as follows:

- As **fasiliteerder** is die pastor ‘n tussenganger tussen God en die mens wanneer God deur Sy Woord na die mens in sy huidige situasie kom.

- As **vroedvrou** en **ko-outeur** help hy [sy] sy [haar] gesprekgenoot om geboorte te skenk aan ‘n verhaal wat nog verborge in hom [haar] leef.

- As **deelnemende bestuurder** skep hy [sy] die veilige ruimte vir die gesprek om sy gang te gaan.

- As **hermeneut** help hy [sy] gesprekgenoot om sy eie verhaal te verstaan en in die lig van God se geskiedenis met mense te herinterpreteer.

- As **tolk** beweeg hy [sy] tussen skrifte en konteks, tussen sender en hoorder in en probeer dit wat aan die gebeur is, te vertolk.

- As **venster** tree hy [sy] op om so deursigtig op, dat sy [haar] eie gesig verdof en dat sy gesprekgenoot die gesig van God kan sien.

- As **deelnemer** word hy [sy] deel van sy [haar] gesprekgenoot se verhaal, terwyl hy [sy] heeltyd rekening hou met die invloed wat sy [haar] eie verhaal op die verstaan van sy [haar] gesprekgenoot se verhaal het.

This position is “deconstructive in its agenda”. It does not permit or allow the therapist to proselytise the one seeking therapy with his/her own beliefs and understanding of either the action, or a pre-understanding, pre-knowledge, expectations about the outcome of the companions’ story, or a predictable ending of the companions’ story. Instead, it invites the therapist to change from a mere manipulative observer into an active participant.

The therapist becomes not only involved in his or her own story, but in the story of the companions as well.

The therapist therefore fulfil the role of a ***not-knower*** who seeks to listen deconstructively to therapeutic conversations in a sphere where deconstructive questioning takes place whilst he/she at the same time, is invited into a process of self-reflection on his/her own emerging narratives.

- *the not-knowing position;*
- *responsive-active listening;*
- *deconstructive questioning;*
- *externalisation and*
- *therapeutic conversation*

The above are essential ingredients in narrative work and will be discussed in the next chapter as I embark on giving a practical account of narrative therapy with people infected and affected by HIV/AIDS.

5.5 IN CONCLUSION

In this chapter I have endeavoured to explore the diverse historical, theoretical and practical themes and shifts around which pastoral family therapy has evolved. The intention was to outline a systematic move from an emphasis on structural/theoretical approaches in therapy to more practical and revolutionary changes in the field of pastoral family therapy.

The transition from individualistic approaches to a more communal approach in therapy is critically explored. This new paradigm (narrative)) puts a challenge to pastoral care. It challenges the world of therapy as well as the pastoral therapist to undergo a fundamental paradigm switch. It challenges the therapist to change from an individualistic approach which was actually a carbon of a systemic approach to an approach that requires that one enters the others, your own, and the contextual world of assumptions, beliefs and values with a deconstructive agenda.

The narrative approach, as a new paradigm for pastoral care, puts us before another challenge: the cultural context of pastoral care. It's no hidden fact that pastoral care operates mostly on the boundary between pastor and congregant (with the emphasis on an "up-down" relationship). This improper balanced position is challenged by the narrative paradigm in therapy. It encourages a commitment to **presence**, **dialogue**, to a **crossing over** and coming back between worlds, to a process of **feeling with**, **thinking with**, and **walking with**.

In this chapter the attempt is to reflect on the value of working narratively, but also to critically reflect on approaches or elements of approaches, which embodies the dimensional or traditional approaches of prevention, information and strategic intend.

This approach is opt for as a framework for doing therapy with the infected and affected for the following reasons:

- It is a move away from an authoritarian approach, which develops an aloofness, which result in distance between therapist and those coming for therapy.

- It encourages the therapist to deal with his or her paranoia first: with his/her fears, uncertainties, prejudices, assumptions, et cetera.

- It encourages a culture of involvement.

- It encourages the therapist to come to grips with his/her own identity, but also with the critical role of showing understanding, unconditional love and acceptance.

- It encourages the therapist not to become the provider of answers to the question why the person is infected or sick, but rather to empower the infected, as well as the effected in the midst of mystery, to query the meaningful nature of relationships with self, others, context and God.

The emphasis of this chapter is therefore on the embarking and exploring of an approach that will enable people to identify and acknowledge problem-saturated stories against God's story. Muller (1996:5) describes this process as a "proses waardeur gepoog word om menslike handelinge, wat verband hou met die verhale van die Christengeloofsgemeenskap, teologies te verhelder en te vernuwe".

This approach emphasizes the facilitating role the pastoral narrative therapist plays in this process. It enables and empowers the therapist to facilitate a process of which he/she is not in control, but in which the therapist **listens**, **asks questions**, **takes a not-knowing position**, and most important, **wait on God's intervention**. Fick (1999:118) reinforces this idea as he writes:

> In pastorale terapie word daar nie na goedkoop antwoorde en vinnige advies gesoek nie. Die nie-weet posisie van die pastor, saam met empatie luister in afwagting op God om op 'n verrassende wyse 'n wending te bewerkstellig, is van die belangrikste terapeutiese beginsels.

In the next chapter the researcher seeks to offer a framework for therapy in order to give the therapist, working with people infected and affected an idea as how to put ideas which were explicated on in this chapter into "practice". Alternative therapeutic ways in working with those infected and/or affected are explored in the next chapter.

CHAPTER 6

ALTERNATIVE WAYS IN WORKING WITH HIV/AIDS INFECTED AND AFFECTED

> *"The knowledge that people are experts in their own lives, adds to a sense of excitement when I meet with people. I am excited by their strengths and abilities ..." (Morgan 1999:14)*

6.1 INTRODUCTION

In this chapter the researcher seeks to offer an alternative way of doing therapy, which will give the therapist working with those infected and affected narratively, an idea as to how to put into practice the ideas, which were explicated on, in the previous chapter. In order to illustrate some of the principles outlined in the foregoing chapters, the researcher will look into the following areas: the ***aim of therapy***; common ***dominant discourses*** in HIV/AIDS stories; the ***effect of the dominant stories*** on the infected and affected; ***deconstruction of the dominant stories***; and the ***essential elements in doing therapy*** with the infected and affected. These elements are: *The not-knowing position*, *deconstructive listening*, *deconstructive questioning*, and the process of *externalising*. These areas of discussion are underpinned with real life stories.

6.2 THE AIM OF THERAPY

The goal of therapy in the case of those being infected and affected by HIV/AIDS, is clearly not to counsel or to take away the disease, or to offer "healthy dogs" – myths about quick fixed solutions and things that work" (Muller 1999:61). Wittenberg (1993:61) summarises the aim for therapy as follows:

> "The counsellor needs to mobilize the spiritual (emotional and human resources would say) to enable the patients (infected and affected) to cope with their physical pain **to understand themselves and their suffering and to be liberated from their social isolation in an atmosphere of acceptance**" (Emphasis: mine)

The idea is therefore to empower those infected and affected to discover their own inner potential which will enable them to work through the myriad stresses, emotions and sense of loss accompanied by the disease. This is clearly not an easy task for both therapist and the companions, but it carries the potential for growth and for healthier functioning in the present and give perspective on a better future.

The aim is further more to "create" a therapeutic framework, in which those infected, affected, as well as those working with them, be empowered to rework or "re-author" the distorted stories around their self-images, identification crisis, stigmatisation, emotional oblusions, as well as family and other significant relationships – so they can accept HIV/AIDS not as **their** problem, but as a problem, and at the same time being guided to see themselves as having a vital role in dealing with what's happening to, with, in and around them. It can therefore be argued that the narrative approach in therapy with those infected and affected is enhanced by an empathic understanding of the centrality of storytelling in **their** life and the meaning it brings to them. The focus of therapy is based on a particular functioning in maintaining the self.

The primary aim is therefore to assist both the infected and affected through **their** life narratives, which mean, in essence, understanding the ultimate meaning **they** give to **their** existence, supporting **their** narratives when appropriate, and when necessary, trying to help **them** reshape **their** stories in the light of meaning which seek to make life more tolerable, as well as more meaningful and abundant to **them** (and not to the therapist).

This aim of narrative therapy is beautifully summarized in the words of Muller (1999:124), as he writes:

> In this type of situation, therapy makes no sense, unless it can in the same way facilitate the hope for a better future. The pastoral therapist is challenged to help people dream dreams in the midst of hopeless situations and to imagine a future to allow them to sing a song again. Even though no change has taken place or no change

> can take place with respect to the present situation, pastoral therapy will nonetheless seek to lead people towards the construction of a story of the future, which is realistic, and make sense.

To achieve this critical aim in therapy, Muller (1999:83) suggests among other things, “five moments” which will help the therapist to conceptualise and orient his/her understanding and appreciation for the meaning the infected and/or affected is making about his/her (their) own experiences.

These moments as described by Muller (1999:83-5) are the following:

- Help the companion(s) to tell **the story of need** as fully and broadly as possible.
- Help the companion(s) to tell **the story of the past** as fully and broadly as possible.
- Discover together with the companion(s) **a future story** in the story of the past.
- Re-interpret the **story of the past.**
- Help the companion(s) to **imagine a story of the future**.

Muller (1999:83) suggests that these moments not be seen as “comparable to steps or phrases” as it will rob narrative therapy from its integrity.

A therapeutic position guided by these “moments” can effectively help those seeking therapy, who already feel powerless against the dominant problem of

HIV/AIDS, to gain a sense of self-control over the problem, but also enables them to move away from self-labelling, self-degrading, self-pity, and negative self-esteem and image. On the other hand, it will help the therapist to become more fully involved with the companion(s) as unique persons with unique stories, In doing this, the therapist is working towards the main objective, which is to understand the critical role of unconditional love, understanding, acceptance, empathetic listening, of showing compassion and being sensitive to the companion(s) as a human being.

The effectiveness of this *five-moment-dance* can nevertheless be blocked by dominant discourses. It is therefore critical to explore some of the common discourses as well as their impact on the infected, affected, and therapy.

6.2 COMMON DOMINANT DISCOURSES IN HIV/AIDS STORIES

As mentioned in chapter one, page 1, of this study, this is a research done about people's real life experiences rather than about statistics. In these stories, I have intentionally refrained from the "questionnaire approach", as I found it as nothing but a clinical analysing of stories or aspects of the HIV/AIDS crisis – rather than an effort to understand the interplay, the dominant stories, and how it converges on each situation. It is therefore of critical importance for the therapist who wish to work narratively, to be aware of the "other" stories. These dominant stories are part of the HIV/AIDS landscape and need not to be ignored.

As therapists we are bound sooner or later to enter the lives of those who had been deeply touched by HIV/AIDS. It is therefore important to briefly examine something of what it means to live in a society where HIV/AIDS is metaphorically seen as a burden on society. We cannot escape the fact that we are shaped and carried by the beliefs, culture and attitudes of our society. These dominant cultures are often laden with powers that prevent us from seeing alternatives.

The following "discourse clues" are picked up from interviews I've had with families, lovers, caregivers and infected companions. These examples portray many dominant stories, which are commonly visible in the life of those infected and affected by the disease. These dominant stories often, if not always, caused those infected and affected to reflect negatively on themselves, their situation and others – and as a result became totally powerless and helpless in the face of the problem. Freedman & Combs (1996:68) writes:

> Many power imbalances in families are coached and supported by power imbalances in the larger culture, imbalances that are supported by the dominant stories about class, sexual orientation, race, gender, and so on.

Following are examples of the common discourses in our society.

6.2.1 Some of the common discourses in society

The Biblical story

- God is a cosmic judge who only gives us what we deserve. Therefore if we suffer, it is because of something we have done for which we must, in justice, be punished.
- God sends us suffering so that we may learn and be spiritually strengthened. Suffering is a kind of test, and when we have learnt enough we pass the test.
- God does have a plan, and suffering is all part of God's plan and purpose. We must just accept it like that.

An ethical story

- HIV/AIDS is a result of being unfaithful to your partner.
- HIV/AIDS is a homosexual problem.
- HIV/AIDS is result of unsaved sex practices.
- HIV/AIDS is a consequence of bad and wrong sexual behaviour.

The cultural story

- Illiterate people are more likely to become HIV/AIDS infected.
- Poor people are more likely to become HIV/AIDS infected.
- Black males are traditionally polygamous and therefore more of a risk group.
- Rich white children are more likely to contract HIV/AIDS as they have more easily access to drugs than poorer kids.

The discriminatory story

- Infected people are not very good workers.
- Infected people are not permittable to get promotions and salary increases.
- Infected people cannot be medically insured since they are regarded as being "as good as dead".
- Infected children must be taught separately since they are ill.
- In schools where infected children are allowed, parents have the right to protest or to withdraw their children from those schools.

The family story

- You don't discuss family problems with outsiders.
- Family members must cover up for each other, no matter what.

- You can only be part of this family if you are willing to keep the secrets.
- We need to protect our family against societal rejection.
- We do this because we love you and don't want you to be hurt.

These discourses have a definitive and profound effect on both the infected and/or the affected. We will therefore explore the effect of the dominant stories on the infected and affected.

6.2.2 The effect of the dominant story on the infected and affected

These dominant stories have the potential to manipulate both the infected and affected in such a way that they find it difficult to see alternative stories. It causes both the infected and affected to internalise the problems around HIV/AIDS. In actual fact, they view themselves as problems. White & Deborough (1998:3) describe the negative effect of the dominant story on a person as follows: "If you see yourself as the problem, there's not much you can do except maybe act against yourself".

These dominant stories emphasize the individuals' as well as the family members' concept that they are damaged, failures, stigmatised and no use. It causes those infected and affected to find it almost impossible to cope with their situation. They are forced by these dominant stories to stay isolated and imprisoned in their own misery.

In listening to those who have been sharing their stories with me, I had been hearing the following themes being instilled on them by the dominants' stories:

- *Fear of rejection and humiliation by partner, friends, colleagues and society.*
- *Fear of losing equal opportunity rights.*
- *The believe that they are disabled and disfigured physically.*
- *Fear of death.*
- *Uncertainty about the future.*
- *Profound rejection by God, et cetera.*

In some of these companions I have heard and noticed feelings of helplessness, powerlessness, confusion, depression, loneliness and negative thoughts. As one was saying:

> *AIDS het my nie net laat al die gewig verloor wat ek nie kan afskud op diets nie – dit het my in 'n mate minder aantreklik gemaak, dit het ook van my 'n huiskuiken gemaak. Ek wonder elke dag, elke nag wat mense van my dink – hulle dink mos almal wat die siekte het is "sluts".*

In the above words of Sheila, I heard a kind of lostness, which is expressed outwardly as anger against others and inwardly against self. Although all of the "wounds" to the infected and affected self-image are critical, the most serious consequence of the dominant stories are when the infected or the family regard him or her as "worthless". I therefore agree with Freedman & Combs (1996:48) as they write:

> Problems develop when people internalise conversations that strains them to a narrow description of self. These stories are experienced as oppressive because they limit the perception of available choices.

According to Menning (1980:313) this "*narrow description of self*", "can lead to depression, self-destructive behaviour and suicidal thoughts".

The effect of the dominant stories, can therefore be argued, is often directed internally, and could be most destructive – not only to the infected individual, but also to the family and other relationships. There is no doubt that all these negative feelings, which are given birth to by the dominant stories, exacerbate the individuals' negative feelings and so doing "feed" the existing problem even further and at the same time prevent the infected and affected from seeing, as Muller (1999:69) puts it:

> ... a surprise turn in events... the "magic" which is so prevalent in our fables... It is not about ways to escape from reality, but rather to discover ways by which we can make sense of reality, which is often difficult to understand.

6.2.3 Deconstruction of the dominant story

Because of the many cultural, social, spiritual, as well as private discourses (or dominant stories), which are associated with HIV/AIDS, constructive and meaningful therapy is often curbed. This presents a pastoral challenge. It challenges the pastoral therapist to adopt a deconstructive agenda when faced with these internal and external powers or forces, which have an ill and limiting effect on the creative ability of people. I wholeheartedly agree with D.J. Louw (1995:41) as he writes:

> The pastoral task, together with the patient [companion(s)] will be: to undo the powers that have the ill effect as a result and the finding of a power that will neutralize and make non-effective that evil that at present is working in the strictness and lastly, the finding of the "culprit" and action to be taken against it.

In taking such an approach, the therapist together with the co-workers, which includes those infected, affected as well as the broader community, combine powers in the reconstruction of new and preferred realities and "in the process the dominant beliefs (and attitudes I would say) and ways of being in our culture are challenged and questioned" (White & Denborough 1998:14). White & Denborough (1998:8) see this deliberate moving away from dominant stories about ones life to preferred realities or stories "as a journey from one identity to another".

According to Freedman & Combs (1996:68), the therapist can "expose subjugating dominant discourses by asking contextual influences on the problem".

The following are guiding questions suggested by Freedman & Combs. I will compliment these questions with sub-questions, which I have used and found helpful in my own work with the infected and affected.

What feeds the problem?

- Tell me about the times when you feel lonely, rejected because of yourself.
- Which places/people make you feel e.g. depressed, lonely, guilty, discriminated against, et cetera?
- Can you tell me a bit about your relationship with these people/places?
- How does HIV/AIDS manage to make you feel bad about yourself?
- What conclusion about yourself have you drawn because of what people might think or say?
- Does these conclusions encourage particular diminishing feelings about yourself or your family, and what are those?
- Does it in any way make the problem worst in terms of your relationship with self, others, family, et cetera? Why?

What starves the problem?

- Did HIV/AIDS ever made you feel good about yourself?
- What does these feelings have you doing?
- Who or what in your life supports you against e.g. negative thoughts, emotions and perceptions of people?
- Can you tell me a bit about your relationship with these people?
- Tell me a bit about things you do that makes you focussing less on what people say or think about the disease.

Who benefits from this problem?

- Tell me about times when you have actually been benefiting from loneliness or having been ostracised by friends.
- Is there any person, group of people or an institution that's benefiting from?
- Tell me about ways in which this illness had improved any relationships (e.g. with family, friends, Church, work, et cetera).
- Did any previously negative attitudes changed because of this problem?

What sort of people would proudly advocate the problem?

- Tell me about a person at work, school or in your family who would team with you in fighting the problem.
- Tell me a bit more about your relationship with this person.
- What does this person most appreciate about you?
- If you see yourself through this person's eye, how would you describe yourself?
- What are you in touch with about yourself when you with this person?
- Tell me a bit about how you're being this way (as described in previous question) contributes to this person's life?
- How would you describe your identity in this relationship?
- Does it make a difference in other relationships?

What groups or institutions would definitely support you against this problem?

- Tell me a bit about a group or institution that's supportive to you.
- What about his group/institution attracted you?
- Can you tell me about your participation in this group/institution?
- What can you see in yourself in reviewing your participation in this group/institution?
- If I could interview other members of this group/institution, what might they tell me about you?

- What is it like having a sense that others see you in this way?

Questions such as these invite people to consider how the entire context of their lives affect the problems created by the dominant stories and vice versa. These questions have the potential and power to unmask or expose the dominant stories that usually block people from seeing the "unique outcomes" in problem-saturated stories. By dealing with it in this way, the negative attitudes, prejudices and negative emotions that comes with the HIV/AIDS "baggage" automatically becomes stepping stones in the reconstruction of new or preferred realities. Muller (1999:109) captures this idea as he writes: "... the disturbed perspectives of the future becomes the primary motivation for meaningful change".

This *unmasking* process of relating problems to societal discourses can enable, empower and motivate people to deal with their problems differently.

Many of the companions I have journeyed with in this research initially believed and viewed themselves as a "mess", "less", "victims", "powerless", "burdens" and somehow "damaged beyond repair". These were undoubtedly "identities" imposed on these people by the many dominant stories. Many had bought into these cultural discourses, and had accepted these views. One of my observations and experiences was that these dominant stories had pervaded their descriptions of themselves so strongly that they were initially unable to identify any information about themselves, which could deviate them from the negative views the dominant stories had imposed and imprinted on their emotions and psyche.

Many of these oppressive perspectives and attitudes were changed after people have been given the opportunity to interact, address and unmask many of the restrains or dominant stories. I therefore agree with (Kamsler 1998:61) as he writes:

> The goal of therapy is to invite clients [companions] to access aspects of their experience of themselves, which have been edited out of the dominant story.

The therapists' task is therefore to facilitate a process through which the companion(s) is assisted to generate alternatives in order to re-tell, and re-author his/her story differently from the initial one who had been influenced by the previously dominant story. According to this approach, people are helped to re-think of problems "as being outside themselves" (Muller 1999:114). The therapist through this approach, reminds companions "of the resources, skills and talents that become available to people when they are invited into re-authoring conversations" (Morgan 1999:14). This process empowers people to disempower the effect of the dominant stories on them.

The therapeutic approach which I champion and which is at the heart of the deconstruction of dominant stories, is the one which takes in account the importance of the **not-knowing position**, **responsive-active listening**,

therapeutic questioning and **externalising conversation**, an approach that's not based on manipulation clever intervention or answer giving, but rather on a therapy process that "is not result orientated, but rather wait-orientated", an approach that "does not offer answers, but facilitates questions and wait" (Muller 1999:74).These elements are essential in doing therapy with the infected and affected and is described in the next section.

6.3 ESSENTIAL ELEMENTS IN DOING THERAPY WITH THE INFECTED AND AFFECTED

When I visited Sarah, one of the companions (in Baragwanath hospital) I have journeyed with for the last four months, she said jokingly to me: "*I hope you not going to preach to me…*" The words of Sarah makes it extremely clear how crucial it is for the therapist to be able to hear what help the people we are concerned with require, not what we, with bias of our own needs, think is needed.

The words of Sarah together with the conversations I've had with both infected and affected made me realize that doing therapy with those infected and affected is about an ongoing journey, neither smooth not predictable. It is about a process that does not fit neatly into a set pattern, or conform to precise categories and that there are no infallible rules, no neat set of guidelines, no invariant prescriptions for the therapist to fall back on. It's about facilitating a process, which takes seriously in account the importance of the following elements:

- The not-knowing position
- Responsive-active listening
- Deconstructive questioning
- Externalising conversations.

These elements prevent therapy from being based on manipulation, clever intervention or answer giving, but encourage a process that "is not result orientated, but rather wait-orientated... an approach that does not offer answers but facilitates questions and wait" (Muller 1999:74). These elements are essential in facilitating a process through which the companions are helped to:

- tell the story of need as fully and broadly as possible,
- tell the story of the past as fully and broadly as possible,
- discover together with the therapist a future story in the story of the past,
- reinterpret the story of the past,
- imagine a story of the future.

6.3.1 The not-knowing position

Prosser (1999:1) gives a very insightful understanding on the not-knowing position as he sees the therapist as:

> an expert in the process of change rather than an expert in the life of the client [companion]. The therapist can never know more about the clients' life (and needs) than the client themselves... The therapist cannot know whether or what change in wanted without asking and does not presume to take a position on the rightness or otherwise of what the client [companion] wants...

If one were to summarise Prosser's words in one sentence, it might be: *"the position of the post-modern narrative therapist is a decentred, but influential role"*. This understanding of the not-knowing position put emphasise on the role of the therapist as helping figure who attempts to put his or her immediate agenda aside and be fully present with the one seeking help. Muller, Van Deventer and Human (2002), refer to this "agenda" as a "deconstructive agenda". This agenda suggests that the therapist free him or herself from constraining frameworks supported and perpetuate by training, theories, counselling and therapy models, ethics, beliefs, et cetera (as described in chapter 2). This agenda therefore suggests a deliberate and conscious move away from a position or stance of knowing.

The question suggested by Freedman & Combs (1996:45) helped me tremendously in achieving and maintaining a not-knowing position whilst I was interviewing and listening to the stories of those infected and affected. It helped me to listen actively and responsively, but at the same time "forced" me to notice and question the assumptions I was making about their stories, their experiences and their life. I constantly asked myself the following questions:

- *Do I understand what it feels like to be this person in this situation?*
- *Am I beginning to fill in the gaps in her [his] story with unwarranted assumptions?*
- *What more do I need to know in order to step into this person's shoes?*

These questions foster in the therapist an attitude of curiosity, and it opens up room for collaboration between the therapist and the one seeking help. This further more leads to a respectful, mutual and subject-to-subject relationship between the therapist and companion. In this relationship, both the therapist and the companion jointly discover new and preferred ways of acting, thinking and being. I therefore fully agree with the writer of the Newsletter of the American Family Therapy Academy, issue nr 74.www.afta.org. (2002:44) that the not-knowing position in therapy is toward collaboration, or a flattened hierarchy" between the therapist and companion.

The not-knowing position does not imply that the therapist is in a "don't know anything" (Freedman & Combs 1996:44) position. Our knowledge is of the process of therapy, not the content and meaning of people's lives. In her address given at a plenary at the Pacific Family Therapy Conference, 2001, Bird made a profound statement that bring an insightful description to the "knowing position" as she says:

> When knowledge is presented to people (clients) in a definitive, comprehensive logiocentric way the following circumstances emerge:
>
> - Knowledge, including alternative knowledge is respresented at static, unified truths.
> - The knowledge is presented as comprehensive and people (clients) may not feel entitled or able to argue against it.
> - The knowledge carriers including the alternative knowledge carriers become the arbiters and gatekeepers of the one truth.

A knowing position can thus be argued is a position which has the potential to exclude the knowledges, experiences, skills, inner resources, practices and ideas that more adequately reflect people's lived experiences. It encourages imposition and infliction of eternal therapeutic powers upon a person who is actually ripe and ready for grasping his/her own meaning through his or her own wisdom and powers.

The not-knowing position is therefore to be striven for by the therapist who wishes to work narratively with the infected and affected. This position reminds the therapist that one does not have to know the answers to peoples' problems in order to be helpful. On the contrary, this not-knowing position invites the therapist to learn the ordinary day-to-day struggles of those being infected and affected by HIV/AIDS, language, values and worldviews of the infected and affected. The therapist is put in a position in which he or she becomes absorbed with trying to understand the sense the infected and or affected made of things.

An excellent summary of what the not-knowing position entails is contained in the way Anderson (1997:4-7) outlines it:

The not-knowing position empowers the therapist to:

- **Become genuinely immersed in and inquisitive about what the client (companion) said.**

  The therapist becomes more focussed on maintaining coherence within the clients' (companions,) experience and is committed to being informed by their experiences and stories.

- **Listens differently.**

  Listens to peoples' experiences as they perceive them to be and not necessarily in a way the therapist understands. The therapist listens not merely to hear, but to become involved in experience of the client (companion).

- **Speak the clients' (companions') everyday language,**

  and not my professional language.

- **Suspend the therapists' pre-knowledge.**

  Suspend the therapists' pre-knowledge and focus on the clients' (companions') knowledge. The more we suspend our own knowledge, the more room there is for the clients' (companions') voice to be heard and for their expertise to come to the forefront.

- **Move from a one-way inquiry towards a mutual inquire.**

  Therapy should be based on a two-way conversational give-and-take process, an exchange and discussion, a criss-crossing of ideas, opinions and questions.

- **Dissolve the need for intervention.**

  As we learn about the language, meaning, direction as preferred by the client (companion), we spontaneously begin to abandon our expertise on how people ought to be and how they ought to live their lives.

- **Value the sense of unpredictability/uncertainty.**

  We have the freedom of "not-knowing", or not having to know.

> Not-knowing liberates the therapist, for instance from needing to know how our co-workers ought to live their lives, the right questions to their problems, the right interventions to make, the outcomes of situations. The stance and attitude allow space for imagination and creativity.

6.3.2 Responsive-active listening

When I visited Sheila (a Methodist local preacher), she was still in the impact stage. When a person is diagnosed as having HIV/AIDS, the impact is tremendous. Shock, denial, severe anxiety and helplessness surfaced clearly throughout my visit. As I was wandering what to say, she said to me "*Leon I am sorry, but I am not in the mood to talk to you right now*". As she was saying that, I was suddenly realizing that it was clearly not the appropriate time for discussion. I changed my approach from "*what shall I say*" to "*how may I learn to listen and understand*". Sheila's statement made me aware of the fact that the listeners' task is not to probe, push or interrogate, but simply to relate, accept, encourage and affirm. In my "stillness" Sheila suddenly started to share with me some of her fears and concerns.

Sheila's reaction made me realize how much the caregivers' ability to express themselves as able and willing listeners give permission for care receivers to communicate what is really important to them. The listening caregiver provides the forum for the care receiver to actualise him or herself in a context of new circumstances. As I was listening to Sheila sharing her genuine fears and concerns, I became aware of myself and began to understand her relationship to her mother, to me, to others, to herself and to the fears and concerns relating to her reluctance to disclose her story to her mother. Freedman & Combs (1996:44) point out the importance of listening in a therapeutic situation as they write: "As simple as it may seem, in the face of prevalent discourses and dominant knowledge, simply listening to the story someone tells us, constitutes a revolutionary act".

Freedman & Combs (1996:46) call this special kind of listening that is required by the therapist, "*deconstructive listening*". This kind of listening enables the therapist to listen to peoples' stories as they perceive them to be and not necessarily in a way the therapist understands. Listening can and should therefore be understood as a prerequisite for more than just understanding. Too many pastors or therapists think that they need (or are expected) to verbally respond to everything the infected and affected say. In my experiences with the infected and affected, I discovered that much of what is said by them do not require verbal response or even understanding, but rather empathetic listening.

In order to achieve this kind of listening, Muller (1999:35) suggests that the therapist should not merely listen to the companions' story in a neutral sense, but that there should rather be "a willingness to become involved in that story". Tim Eberhart (1996:24) expresses some significant reflection on the art of responsive-active listening as he writes: "As we listen, we become aware of ourselves and begin to understand our relation to others and their relation to us". Through responsive-active listening both teller and listener become drawn into each other's space or worlds.

Responsive-active listening therefore means that the therapist should:

- listen to peoples' stories as stories,
- "listen with our ears cocked and our mouths set to say Aha! When we recognize a "clinically significant item" – something that we know what to do with" (Freedman & Combs 1996:43),
- listen not to advice, but to understand their stories in a way in which they want it to be understood,
- listen "with focussed attention, patience and curiosity while building a relationship of mutual respect and trust (Freedman & Combs 1996:44),
- listen to relate, accept, encourage and affirm rather than to probe, push or interrogate,
- not listen in order to make a diagnosis.

The art of listening can therefore be summarized by the following quotation of Daniel Louw (1991:46):

> The willingness to listen is the willingness to remove the risk for others so that they may receive the gospel at the deepest level of life. It is a willingness, which requires time, effort, energy, and above all, the love, which tunes in to another person's situation.

The narrative therapist should therefore always be aware of the fact that story listening is not only vital; it is the essence of therapy. For the companions, to be able to tell, re-tell and re-author his or her clouded and problem-saturated stories of fear, loss, grief, stress, stigmatisation, and other stories related to HIV/AIDS, rely "upon the presence of an empathetic self object to be with him or her, to confirm and validate him or herself via the story" (Randal 1986:213).

6.3.3 Therapeutic questioning

As in the case of listening, therapeutic questioning is the therapist's effort to understand life stories of both the infected and affected, but also to unmask or expose some of the subjugating dominant stories which are emphasizing the concept that the infected and affected are damaged, a failure, or stigmatised and so doing prevent them from seeing alternatives to their problem-saturated stories.

Freedman & Combs (1996:57) write:

> Deconstructive questioning invites people to see their stories from different perspectives, to notice how they are constructed (or that they are constructed), to note their limits, and to discover that there are other possible narratives.

Therapeutic questioning can therefore be regarded as essential as it enables the companions to see that those limiting narratives are not inevitable and that they do not represent essential truth.

In other words they are constructions that can be re-constructed differently.

The following are conversational questions that should not be asked merely to gain data or information, but to be therapeutic. Questions become therapeutic in and of themselves if they are asked:

- "to generate experience of preferred realities rather than to gather information" (Freedman & Combs 1996:113)
- to keep the therapist in a not-knowing position rather than in a position of power
- not from a position of pre-understanding or as Freedman & Combs (1996:118) writes: "we endeavour not to ask questions that we think we know the answer to, or ones that we want particular answers to"
- not to probe, push, manipulate or interrogate the one seeking therapy in a direction determined by the therapist. Freedman & Combs (1996:118) reminds us that "although we may have a particular idea in mind when we ask a question, the person who answers it determining the direction it will take"

These questions should therefore invite people not only to tell their stories of need, but also to trigger people to discover, rediscover and use their own resources in the process of re-authoring "their own future stories around their own pots of honey" (Muller 1999:22).

I whole-heartedly agree with Kamsler (1998:65) as he defines the position of the therapist as question facilitator as follows:

> The emphasis here is on the idea of the client [companion] as the expert, with the therapists' role being to ask questions, which generates unique outcomes and new stories. This is in contrast to more traditional ways of doing therapy where the therapist is seen as the expert who has the knowledge to diagnose and fix the client's [companion's] problem.

I found the five categories of questions as suggested by Freedman & Combs (1996:121-39) very helpful in doing therapy with both the infected and affected as it has the potential to help them unpack their stories or see them from a different perspective, so that *how* they have been constructed becomes apparent.

Freedman & Combs (1996:119) divide these therapeutic questions into five major categories, namely:

- *deconstruction* questions
- *opening space questions*
- *preference questions*
- *story development questions and*
- *meaning questions.*

These questions are of immense value in the process of externalisation. Examples of these questions are given in the next section. These questions invite the infected and/or affected to:

- unpack, unmask or expose the dominant stories they might be experiencing,
- constitute the unique outcomes, sparkling moments, or preferred realities that do not support the dominant problem-saturated story,
- justify the alternative choices they have made and encourage them to describe their motivations. In other words, it allows the infected and/or affected to clarify and elaborate on their preferred directions in life,
- experience their lives and themselves in new (alternative) ways as they focus on previously neglected and unstoried aspects of their experiences,
- reflect on different aspects of their lives, their stories, various relationships, preferred directions, et cetera. It encourages people to take responsibility for constructing their own new beginnings.

These questions play a critical role in therapy as it opens up a very natural place for the companions to tell (Muller 1999:84):

- *The story of need as fully and broadly as possible.*
- *The story of the past.*
- *The future story in the story of the past.*
- *The re-interpreted story of the past.*
- *The imagined story of the future.*

These questions together with the **not-knowing position** and **responsive-active** (deconstructive) **listening** are instrumental in creating a therapeutic conversation, namely, externalisation that has at its very locus a requirement for improvisional dialogue. This therapeutic "method" as described and outlined by Muller (1999), White (1988/9), White & Epston (1990) and Roth & Epston (1995/6) is elaborated on in the next section.

6.3.4 Externalization as "method" of therapy with the infected and/or affected

As we have seen, many stories in the dissertation bear witness of the fact that many individuals and families who are affected by HIV/AIDS are victims of internalization. There is no doubt that many of the negative feeling generated by and around HIV/AIDS, exacerbate the infected's and/or affected's negative feelings about themselves. It emphasizes the individual's and family's concept that they are damaged, failures, stigmatized, sinners, "rejects", worthless – the problem.

I think it is perhaps worthwhile repeating some of those internalised stories here. These are abstract from the conversations as portrayed in the actual stories in this dissertation:

- *"I feel like a "slut""*
- *"HIV laat my vuil voel"*
- *"This is my deserved punishment"*
- *"I have let my family down"*
- *"As parents we have failed to learn our children good values"*
- *"HIV/AIDS laat my "sorry" vir myself voel"*
- *"Who would want to employ a sick and dying person – I will be no good any way"*

Freedman & Combs (1996:48) are of the notion that:

> Problems develop when people internalise conversations that strain them to a narrow description of self. These stories are experienced as oppressive because they limit the perception of available choices.

Externalising is an approach to therapy that emphasis the vital fact "that the person is not the problem, but the problem is the problem" (White 1989:20).

We can therefore come to understanding that externalisation is an approach to therapy that encourages people to see problems as separate from them. In this process, that which is perceived as the problem becomes a separate entity and thus external to the person or relationship that was ascribed as the problem.

As seen in the many stories told in this dissertation, HIV/AIDS infected and/or affected people see and think of the problems resulting from HIV/AIDS as integral parts of their character, identity, or the nature of their relationships. These approaches to the problem "limit the [their] perception of available choices" (White 1989:20). Externalization on the other hand, helps them to render less fixed and less restricting power to those problems that are considered to be inherent. Through the process of externalisation, the person(s) are empowered to move away from the dominant stories that have been shaping their lives and relationships. The infected and or affected no longer defined him/her (them) as inherently the problem, but see the problem as something outside themselves over which they can exercise control. The problem can now be reflected on, and erratically evaluated by the infected, affected, significant member and friends.

As White (1989:6) has commented, externalising conversation “frees persons to take lighter, more effective and less stressed approach to “deadly serious” problems”.

The therapist has a very definitive and distinctive role in the externalising process. Roth & Epston (1996:149) describe this role as follows:

> We do not see externalizing as a technical operation or as a method. It is a language practice that shows, invites, and evokes generative and respectful ways of thinking about and being with people struggling to develop the kinds of relationships they would prefer to have with the problem that discomfort them.

Roth & Epston therefore suggest that the therapists’ focus should be on values, hopes, and preferences, rather than on pathology. The therapist’ role, in the process of externalisation, stand as an alternative to the traditional diagnostic role of the therapist. The focus in the externalising conversation is on expanding choice and possibility in the relationship between the person and the problem and not on solving the problem for the person. The role of the therapist should therefore be to listen, ask questions, be present in a way that will:

- invite the infected and affected to give their perception of what the problem is,
- detangles themselves from the problem(s),

- reduce the influence/power of the problem on them,
- empower them to foster a different self-definition of themselves,
- encourage the infected and affected to use their voice to his/her [their] advantage. To see and make choices,
- let them discover a new knowledge about themselves. To see themselves through the "eyes" of this new knowledge as more than a person(s) infected or/and affected by HIV/AIDS. The therapist must help them to be in touch and in dialogue with who they want to be (humour, a social life, hobbies, interests, et cetera),
- empower them to top into a wealth of power and strength that lay deep within them.

Michael White (1995:41) summarizes this critical role of the therapist beautiful as he writes:

> I think the main point about externalising conversation is to introduce a different way of speaking about, and a different way of thinking about that which is problematic – and of course, a different way of acting in relationships which is problematic.

The infected and/affected should therefore be engaged in an externalising conversation. The following "steps" as described by Muller (1999:115-118) and Epston & Rath (1995) can be used as basis to illustrate how the therapist can initiate an externalising conversation with the infected and/or affected.

Step 1

Give the problem a name.

The therapist and the infected and/or affected must engage in a search for a suitable name for the problem. By doing so both therapist and infected "club" against the problem.

The problem might be named "fear", "guilt", "isolation", "social phobia", "self-pity", "anger", "self-blame", or any other name given by the infected (or by both the infected and therapist).

Examples of questions:

- *What would you call this thing that you have been struggling against?*
- *How would you describe what it is that is holding you back?*
- *You mentioned "isolation", would that be the best label for what has been oppressing you? If so, can you say a little more about just exactly what "isolation" means to you?*

These questions invite the infected and/or affected into conversation with the externalised problem. In this conversation the "problem" becomes regarded as a "thing" with which the infected has a complex, but mutual relationship. The person is no longer the problem, rather the person is struggling with a problem – in other words the infected is no longer “isolated”, but struggle with isolation. The problem is separated from the person. By naming the problem, the “problem” is changed from being an adjective that describes the person (e.g. I am a “rejected” person) to being a noun that plagues the person (e.g. “I struggle with rejection”). Neuger (2001:90) writes: “The more that the problem can be externalized, the more likely the counselee can generate resources to resist it”. The role of the therapist is therefore to listen to the story not in order to solve the problem, but rather to discover the externalized problem as the infected describes it and to find ways to disempower the problem by empowering the resources of the one struggling with it.

Step 2

Map the effects of the externalized problem.

Invite the infected and/or affected to relate to the externalized problem through different domains of living. Implicate personal agency by connecting the effects/influence of the problem on their lives and relationships. The idea here is to invite the infected and/or affected to inquire about all the negative plans, intentions, actions, tactics or “tricks” as characterised by the externalized problem.

Possible questions to ask:

- *How does "anger" make itself known to you?*
- *What has the reputation got people (friends, church, people, family members) thinking about you? What has it got you thinking about yourself?*
- *What is it like when "self-blame) make and unexpected appearance?*
- *How does "depression" come between you and your mother? (wife, children)*
- *What does the HIV/AIDS voice tell you about yourself or whisper in your ears about what other people think of you?*
- *What does "low-self esteem" keep you from doing?*
- *You said earlier that you would like to tell you others about your HIV-positive status does "fear for rejection" make it easier or harder for you to tell others?*

Step 3

Evaluate the effects of the externalised problem.

Encourage the infected and family members, friends to evaluate the effects that were listed in the previous step. This new knowledge will bring to the surface new self-descriptions once the impact of the effects has been made "public" and acknowledged by the infected and affected. This new knowledge may replace the descriptions based on earlier relationships with the problem.

Possible questions to ask:

- *Do you like/dislike the way "anger" makes itself known to you? Is this a way you/others appreciate?*
- *You say "isolation" keeps you away from others. Is it a good or a bad thing?*
- *Do you like "depression" to come between you and your parents?*
- *Does it make you happy, sad or something else when "fear" keeps you from going to church?*

These questions will help the infected ad/or affected to see hear and experience the externalised problems' effects on them and on their relationships, but it will also empower them to make conscious decisions in terms of what they prefer and what they don't. This process detangles the hold of the problem narrative and almost immediately makes room for a host of alternative frames for the infected and/or affected.

Step 4

Encourage them to justify the evaluations made.

Invite the infected and/or affected to relate to the externalized problem through, their own practical knowledge, rational, and emotional abilities. Through this process the infected and/or affected are empowered to take a deconstructive position against the problem. It makes the infected and/or affected aware of the fact that they have within them the knowledge and resources to make choices and in so doing, create preferred ways of dealing with the problem. It therefore helps people to gain both "voice" and "agency". The more they know about the problem, the more effective they can deal with it.

Possible questions to ask:

- *Why do you think "anger" is something you don't want in your life?*
- *Tell me a bit about why you don't like it when people pity you?*
- *Why does it make you sad when self-inflicted "isolation" keeps you from going out with friends?*
- *What make it so painful for you when "anger" makes you to shout at your mother?*

Step 5

Invite them to recall occasions or situations when the problem did not dominate them.

Such occasions are when they have succeeded in allowing the problem to disrupt their lives. These “success” stories can come from themselves, from family members or friends. These stories will empower agency in the infected and affected and thus create a therapeutic environment in which the one seeking help discover that he/she (they) have within them the knowledge authority and the resources to keep the problem under control. They can face the externalised problem “with a sense of being a subject in her [his, their] narrative(s) rather than a character written and manipulated by outside forces” (Neugar 2001:91).

Possible questions to ask:

- *Has there ever been a time when “HIV/AIDS” could have taken control of your relationship with your husband, but it didn’t?*
- *Have you as a family ever stood up to some of these cultural expectations and decided to do things your way?*
- *Even though HIV/AIDS status convinced you it was too risky to go out and be among other “negative” people, did you ever hold out against its arguments longer than you had at other times?*
- *In the last month or so, “self-pity” really seems to have dominated your social life, but were there any points at which, even for a moment, you stopped feeling for yourself?*

Step 6

Map a history of the infected/affected's knowledge/ability/resources against the problem.

The therapist, co-operating with the infected and/or affected, seek to discover historical evidence, which points to competence and potential to take a stand against the externalised problem. The therapist facilitates a process through which both the infected and affected seek to find stories in the past to show and support the idea that they are actually competent to deal with externalized problem(s). Freedman & Combs (1996:122) is of the opinion that "history of relationship questions can reveal taken-for-granted or embedded practices or knowledges". History mapping open up space for unique outcomes to be explored.

Possible questions to ask:

- *Tell me a story of your past which can help me understand how it is possible for you to resist being controlled by "self-blame" ...*
- *What particular things would I have noticed if I were there when you were putting "anger" in its place?*
- *Did other people play a part in helping you to control "self-withdrawal"? How did they do it? (ask them to give an account)*

- *You've said that, even though moods of hopelessness often lead you to suicidal thoughts, you know that you don't really want to die. When was the last time this knowledge helped you turn suicidal thought away?*
- *When was the last time you got yourself out of the house? What steps did you take and was there any positive experiences in your "outside-of-home" life you would like to share with us? Who helped you in doing that, and how?*
- *Now that I understand "angers'" foundation in your past, do you see any "tools" that might help you dealing with your current experience? How?*

Step 7

Provoke speculation regarding an imagined future.

The therapist attempts to provoke speculation regarding the type of future, which can be expected from a person, or family who can act competently and with strength against the externalised problem. A story of the future must be imagined.

Possible questions to ask:

- *If you continue to offers such resistance to "feelings of worthlessness", what will your life be like in three months time? What would your relationship be like with your work, family, friends, et cetera?*
- *Do you have any thoughts about how you could put "depression" in its place in future?*
- *You told me about how you had overcome "loneliness" in the past, how can you use this knowledge, ability to overcome it in the future?*
- *How do you think it will shape your life in future?*
- *What will this focus make possible in your relationships in future?*

This speculation and exploration of positive "forces" contribute to a new and high valued identity of self and it might provide the infected and/or affected, with some more avenues for alternatives or preferred outcomes.

Step 8

"Create" an audience.

Invite the infected and/or affected to contribute his/her [their] knowledge and abilities to an archive (an audience) in which their knowledge and abilities can become further legitimated by its potential for making a contribution to others who are involved with similar problems. An audience must be recruited who can offer “applause” for the new identity and new story, which is being developed. Since the problem developed within a social context, it is necessary to arrange matters in such a way that the social environment can be utilized to offer appropriate support.

One can ask about family or friends who knew the person before the problem influenced him/her (them). The idea would be that the infected and/or affected would be able to tell someone else about what had been attained thus far and in this way engage this person or persons not only as an audience which offer applause, but who can also form a system of support.

Possible questions to ask:

- *If you had a friend or family member who supported this new direction in your life, what would they be like?*
- *Is there a teacher, an uncle, grandparent, or other person who knows something about you that will help you deal with this problem?*
- *What exactly about this person(s) make you feel appreciated and/or understood?*
- *What did that person(s) know about you that you sometimes don’t know about yourself?*
- *Who in your future will be most pleased by the way things have developed as these changes continue to unfold?*

- *Given these people we have been talking about, what would be the next step to make them part of your army against this problem?*

6.4 IN CONCLUSION

In this chapter I have tried to emphasize the facilitating role the post-modern narrative therapist should take when working with the infected and/or affected. The therapist facilitates a process of which he or she is not in control, a process in which collaboration between the therapist and the one seeking help, is highlighted as core element for therapy.

In my first hand dealing with HIV/AIDS infected and affected people, I became increasingly aware of how wasteful it is to therapy time when ones focus is to change people without their permission or need for change. This chapter puts the spotlight on therapeutic "tools" which suggest alternative ways that do not seek to overcome any objective truth, but rather to co-create meaning through the way we listen, ask questions, encourage, reflect, paraphrase and summarise experiences. It underpins therapeutic building blocks that enable the therapist to listen, take a position of not knowing, ask questions and most importantly, wait on God's intervention. This stance is beautifully summarised by Fick (1999:118) as he writes:

> In pastorale terapie word daar nie na goedkoop antwoorde en vinnige advies gesoek nie. Die nie-weet posisie van die pastor, saam met empatiese luister in afwagting op God om op 'n verrassende wyse 'n wending te bewerkstellig, is van die belangrikste terapeutiese beginsels.

The narrative pastoral therapist embraces a position that begins to objectify problems and situate them in a way that will eventually open up space for God's story to enlighten and renew the story of the troubled person. The main focus of this chapter is centred in the following words of Morgan (1999:14):

> These stories are special because they remind me that I don't have to know the answers to peoples' problems to be helpful. They remind me of the resources, skills and talents that became more available to people when they are invited into re-authoring conversations. Remembering these stories and the knowledge that people are experts in their own lives, adds to a sense of excitement when I meet with people – I'm excited by their strengths and abilities. I look forward to them.

CHAPTER 7

A CRITICAL REFLECTION ON THE STUDY

> *"When we reflect … on unique outcomes, on the effect of various practices, on preferred directions in life, or on any aspect of therapy, we are doing co-research" (Freedman & Combs 1996:289)*

7.1 INTRODUCTION

Freedman & Combs (1996:169) write: "It is through the experience of reflecting on our experiences that we make meaning of it". As narrative therapist and researcher I believe that reflection is a particularly necessary process as it becomes a post-modern or social constructionist ethics in which the therapist/researcher and those coming for therapy function. The ethical postures on which reflection is based values *openness, transparency, decentring* of the therapist/researcher, *subjective-integrity*, *honesty*, and the *deconstruction* of any power relationships that might exist.

Freedman & Combs (1996:186) describe the importance of critical reflection as follows:

> A characteristic of our therapy (and research I would say) and probably of therapy (and research) using narrative ideas – is **a movement between direct experience and reflecting**...
> (Emphasis mine)

Reflection can therefore be argued, serves as a "tool" which the therapist, researcher and those in therapy or research use to interact and evaluate their experiences. It invites people to reflect on their own emerging stories, but also on each others emerging stories. Reflection opens up space for the sharing of knowledge, for evaluative listening of various understandings of different stories and for constructive comments to be made on those understandings, which are found useful and fitting. This practice according to Karl Tomm (1988:54) leads to "empowerment" of all the stakeholders.

The practice of reflection in therapy and research fits with the principles implied by Narrative therapy/research, namely:

- It invites people to see themselves as experts on themselves.
- It offers people a sense of community and collaboration.
- It requires the therapist/researcher to enter the "world" of the companions not as an observer, but as a participant.
- It reflects a change in ideas about balance of power.
- It encourages critical reflection, integrity, and honest introspection.

The purpose of this chapter is therefore to emphasise the importance of reflection as an important learning activity. This activity identifies and reinforces the continuous learning process for both the therapist (researcher) and those coming for therapy. Reflection on research, therapy, the position and role of the therapist, and those in therapy as well as theology, was done continuously throughout the study. Snidle and Welsh (2001:150) reinforce the importance of reflection as they write:

> The purpose of pastoral care is not merely interviewing, but to provide conditions that facilitate ***VOLUNTARY CHANGE AND GROWTH***. Always remember pastoral care is NOT the giving of information, ... and it is not just the giving of advice. Neither is it the influencing of attitudes by persuading, leading or arguing. It does not change behaviour by admonishing, threatening, warning or compelling. (Emphasis mine)

The above quotation emphasizes the fact that reflecting practices are practices that counteract the hierarchy implied by our position as therapists, research models, theology and by the perception of those coming for therapy. The following areas are being reflected on in this chapter:

- A critical reflection on the research/therapy.
- The researcher/therapist.
- The theology of HIV/AIDS.

7.2 A CRITICAL REFLECTION ON THE RESEARCH

The first observation I would like to make is that research and therapy are not viewed as two separate entities. That which apply for one, applies automatically for the other. The two concepts are used interchangeably. The same is applicable for the concepts researcher and therapist. The idea with this research was to **do** and **think** differently about the way in which research and therapy are to be done. The aim with this research/therapy was particularly done with the deliberate intention to move away from the old paradigm where the researcher is indoctrinated to do research in a diagnostic, pathologizing, analytical and problem-driven enterprise. This old paradigm is described by Sekaran (1992:4) as follows:

> Research can be described as a systematic and organized effort to investigate a specific problem that needs a solution. It is a series of steps designed and followed, with the goal of finding answers to the issues that are concern...

Cohen & Manion (1994:40) reinforces this old paradigm as they write:

> Research is also a process of arriving at dependable solutions to problems through the planned and systematic collection, analysis, and interpretation of data. It is also a tool for advancing knowledge, for promoting progress.

The research paradigm described in above quotations turns research and therapy in an activity that:

- is based on rectifying or correcting,
- delineate the factors that are associated with the so called problem,
- involves a series of well-thought-out and carefully executed activities that will enable the researcher to know how problems can be solved or at least minimized.

Research according to this paradigm, thus encompasses the process of inquiry, investigation, examination, experimentation who have to be carried out with preciseness, systematically, objectively and logically, with the expected end results to discover new facts that will help the researcher to deal with problem situations.

In this research, the researcher dealt with people being infected and affected by HIV/AIDS. The researcher constantly and inevitably had to deal with questions such as *"Who am I*?"; "*What is my purpose in life*?"; *"What is the meaning of my illness*?"; "*Why is God punishing me/us*?", et cetera. HIV/AIDS raised many questions for which the researcher had no ready, miracle, or quick fixed answers or solutions. The researcher therefore had to refrain from a research model as described by people like Cohan & Manion (1994), Sekaran (1992) and others who function in a "*knowing*" paradigm.

The “model” preferred, and used in this research, is the model based on a “model” as developed by Freedman & Combs (1996); Muller (1996, 1999), Muller, van Deventer and Human (2001), called the narrative/social constructionist paradigm in research. (This paradigm has already been extensively described in chapter 1). Working from within the framework of this paradigm, the researcher felt more comfortable and ethical by learning from the companions, and the meanings they prefer to bring to their stories. The research is therefore less concerned with a “systematic and organized efforts to investigate a specific problem that needs a solution” (Sekaran 1992:4). This approach to research, made research to be a collaborative activity by means of which a given phenomenon or reality is shared and experienced in a manner that embraces subjective-integrity, rather than “a structured inquiry that utilises acceptable scientific methodology to solve problems…” (Grinnell 1993:4).

The researcher therefore intentionally refrained from any form, which could possibly turn the companions into objects of research or therapy. The researcher intentionally refrained from:

- **Interviews that seeks objective information** in the form of facts rather than experience. In such interviews the researcher often control the situation in such a way that the interviewee does not digress from what the researcher had in mind. Thus open space for subtle manipulation from the researchers’ side.

The researcher nevertheless conducted many interviews. These interviews were conducted in a fashion that promotes the social-constructionist character of the research. Van Deventer (2002:6) in his paper: "***Unheard stories of people infected and/or affected by HIV-AIDS concerning care and/or the lack of care***", writes about the importance of **conversational interviews** as follows:

> In this way the social-constructionist character of our research takes shape from the outset, while conducting free ranging and in depth conversational interviews with individuals and groups will further enhance the narrative nature of the project [research]. Such narrative conversations require three basic points of departure: **The non-expert-not-knowing position, responsive-active listening** and **conversational questions.** (Emphasis mine)

These conversational-interview questions were categorized in *background questions, central-peripheral sampling questions, mapping questions*, and *discourse questions* (as used and described in chapter 2).

- **Questionnaires:** The researcher totally retrieved from using questionnaires in his/her research. The questionnaire promotes a feeling and position of investigator versus respondent; object versus subject relationship; factual information versus real experiences; statistical data versus conversation (experience). Questionnaires in the researchers opinion pre suppose that the researcher is separate from,

> and able to control those "being researched". Questionnaires have the potential to create the idea that the researcher can make detached, objective assessments of what is wrong and fix it; or that the researcher could design a strategic intervention that would disrupt and redirect what's wrong with the research object.

In this research the researcher opted for an approach which "permitted the patients' [companions'] to use his [her] own thinking, his [her] own understanding, his [her] own emotions in the way that best fits him [her] in his [her] scheme of life" (Freedman & Combs 1996:9) (as described in chapter 1 under: "positioning of the study").

The aim with this research was therefore to invite those infected and affected by the HIV/AIDS to enter into meaningful conversations. This dissertation is therefore not a result of "statistical" research, but rather the result of meaningful conversations between the researcher, the therapist and those infected and affected.

The following verbatim report was recorded between the researcher [therapist], an infected and a family member, and the matron of a Johannesburg hospice, who does not want her name or the name of the institution to be recorded for ethical reasons. Names and minor details have been changed to obscure the identities of those participated in this verbatim report. This report was recorded on Saturday, 3 August 2002.

The researcher had been working in the context for the last ten months, since November 2001, and had been visiting the hospice twice a month for approximately two hours per visit.

Researcher: *Good morning Matron, and morning to both of you. Thanks for having set aside an hour to accommodate me. As I've mentioned last week – this time will be used to share a little bit on how we have experienced the ten months together. Please feel free to share anything, any experience, incidents… et cetera, which you think might help us to develop some understanding of how we have perceived what, happened over the last ten months. I am very curious to find out your opinion on this.*

Matron: *(laughing) Let me start by making a confession … When you came here last year and telling me about what you want to do, I was honestly on the point of "throwing up". I just had enough of people coming here and abusing and interrogating my patients. I thought you were one of those "aasvoels bende".*

Researcher: *(jokingly) "Aasvoel bende"? …*

Matron: *Yes. Those who come here month after month to take their piece of flesh and you never see of them again. I am talking about all the students coming here to do research.*

Researcher: *I am just very curious now. Forgive my curiosity, but how… how did it come that you have had such views about those coming to do research? I mean the "aasvoel bende" is an interesting metaphor you using here…*

Matron: *It was always about what they could gain from us, you know what I mean. They would phone and send lots of forms that had to be completed by myself, my staff and my patients – you see them once or twice, when they collect their forms or when they want to ask for more information – then that is the "laaste sien van die blik kantien".*

Researcher: *Yes john… (*John has been diagnosed with full-blown AIDS and is in the hospice for 15 months now).

John: *I agree with Ma (referred to Matron). You see them whole year, but they have all different faces. When I hear the word student, I feel like running away or hiding somewhere. They make you tired with all those questions and paper work.*

Researcher: *And what about you Suane?*

Suane: (the youngest sister of John. John stayed with her and her husband until he became very ill and moved in here) *It's true what they saying. I use to become very angry when I saw them speaking to John.*

Researcher*: Would you mind telling me about… about that which changed your perceptions?*

Matron: *The way you do things …*

John and Suane: Nodding their heads in agreement with the matron.

Researcher: *Thanks. Remember what I always say, "we are partners…" You have contributed as much as I have to whatever good that have occurred …*

Suane: *(interrupting) but you were part of us and that made a huge difference.*

John: *She's right, you were like our buddy … I hope you'll do my funeral … (laughing)*

Matron: *You filled our Saturday afternoons with much joy and meaning. I hope you not going to stop coming here after you have completed your studies.*

Researcher: *You make me feel very humble… Thanks, I value what you're saying to me today. I hope I can continue to be one of this family but we'll talk about that at some other time…*

This was just a part of our reflective discussion. This very same discussion was continued with other individuals, family members as well as in groups.

This process was fairly lengthy and would be not practically possible to reflect in this limited space.

In conclusion, the research and therapy was conducted to give an academic, practical scientific account of the research done, but most importantly, to reflect as to what extend it had been beneficial to the co-workers (those infected and affected, but also to those working with them and caring for them). This research/therapy was not focussed on bringing answers or solutions to the many complexities of HIV/AIDS, but rather to give people the opportunity to communicate reality and revelation of the previously untold and unvoiced stories.

7.3 REFLECTION ON THE RESEARCHER/THERAPIST

In chapter 1 (1.2), I've given an elaborated view on the position I have chosen to take in this study, namely the narrative-social constructionists position. This position was representative of the paradigm I use to have organized my thinking and work as therapist and researcher. Looking back, I now view my work from a few years back as guided by an "*up-down*" position. This view presupposes that the therapist or researcher is separate from those coming for therapy or being researched. Freedman & Combs (1996:3) is of the opinion that such a position makes the researcher or therapist feel "that they can make detached, objective assessments of what is wrong and fix problems in a way analogous to the way a mechanic fixes a malfunctioning engine".

It's perhaps wise to pause at this point and tell my own personal story that reflects some of the ideas, practices, attitudes and discourses that supported and guided that "up-down" position I use to function in.

As teacher I was trained and conditioned in the two golden rules:
***Rule one**: "A teacher is never wrong".*
***Rule two**: "If a teacher happens to be wrong, refer to rule one" (which says a teacher is never wrong). A good teacher, in my opinion, was the one who always knew the answers to the various problems. This became a dominant discourse, even in my ministry. In 1995 I became the minister (pastor) of Brixton Methodist Church. As young minister, I was confronted with many day-to-day pastoral issues. Words such as "I cannot cope in the marriage"; "I feel such a failure"; "Why is this happening to me"; "Does God hear my prayers"; et cetera, were part of my "daily bread". As young pastor, I resonated with my own sense of inadequacy when faced with such words. I wanted to make things better, I wanted to fix and correct things, I wanted to succeed as pastor. My study (counselling room), Bible, my calling, my black suite and clerical dog collar protected me against the terrible "sin" of being wrong. So I tried harder and harder not to appear inadequate, not to disappoint those in need of **my** answers and **my** guidance and not to appear stupid in front of them.*

I eventually became more and more convinced that I was called to design strategies that would make people feel and live a better quality life. My responsibility, so I thought, was to give guidance, was to control, to give answers, was to set goals and drive people towards it. People possibly accepted whatever I threw on them. They had to, because, in retrospect, I am the servant of God, who stands and speaks in the authority of God, the prophet who knows the future, the pastor who knows exactly how people feel, the preacher who knows the Bible which contains all the answers and solutions to their troublesome lives. This was my understanding until I found myself in a "down-position". In my Masters studies I gave an account of this "down-position". Following is an abstract that gives a summarised version of a situation that converted my thoughts and practices, my view of people and their problems and most of all, my understanding of my role as pastor and therapist.

"After seven years of "miracle" doctors, specialists, drugs, operations, investigations and even more tests, financial, physical and emotional strains, my wife and I came to the painful reality that, unless God miraculously intervene, conceiving children of our own would be impossible… The dream we had harboured for years, came to screaming halt with the words of the specialist at the FEMINA infertility clinic, in Pretoria: "Sorry, but it seems to me as if there is no possible way for you to conceive biological children" The infertility testing was discontinued and we were left with the blunt fact – you are INFERTILE. (H L Klein: 2000:3)

This situation made me to retreat in the position of those I've seen on a daily basis. For the first time I experienced, what they must have experienced when they were sitting in front of me – helplessness, powerlessness, confused, angry, rejected, in denial ... This phenomenon had made me to realize that there is no quick fixed answers, miracle solutions, no special privileges, no "up"-(power) position. My wife and I had found incredible healing in the sharing of the painful reality, with each other and with others. (This only happened during end of the M-research). This experience invited me as therapist and researcher to no longer speed energy on trying to solve problems, to fix "broken parts" or to provide answers and solutions to peoples' problems. It made me to realize that the therapist or researcher facilitates a process of which he/she is not in control, but rather a process in which the therapist or researcher listens, takes a not-knowing-position and asking questions in such a manner that the companions understand the ultimate meaning **they** give to **their** existence and "to be in control of **their** own destiny" (G Larner 1998:551). (emphasis:mine)

As I look back on the research reported in this dissertation, I realize to what extend the narrative-social constructionist position had influenced and guided my way of doing and thinking about research and therapy with those infected and affected by the HIV/AIDS. During the regular PhD group meetings, reading up of narrative material, field research, the engagement with real life stories of those infected and affected, I found the narrative ideas and practices more intriguing and appealing. This was not by any means an easy or automatic shift. I must admit, at times I felt like retrieving to the old ways of doing things. This became an unattainable quest and an overwhelming struggle between the "*old*" and "*new*" ME. However, when thinking and doing narratively, I felt the incredible feeling of being responsible, relaxed and ethical. I therefore agree with Freedman & Combs as they write: "Coming from a "not-knowing" position made me feel more comfortable and ethical by learning from the clients how their stories unfolded" (Freedman & Combs xii). In the beginning this position felt very, should I call it, "not right"? How could I, the one being called by God to solve their problems and to have answers to their problems-saturated questions, tell people that I don't have all the answers? And yet, it was such a great feeling being able to collaborate with them not as my inferiors, or the ones I have to fix, but as my companions, partners, co-authors and co-workers.

To be faithful to the narrative-social constructionist position, I had to constantly reflect on *what* and *how* I was doing things. The ongoing and continuous reflection helped me to make deconstruction a conscious and necessary practice. The following questions suggested by Freedman & Combs (1996:40) were most helpful in attaining this role: I've already mentioned these questions in chapter 1, but feel it is worth the while mentioning here again.

- *Am I asking for description of more than one reality?*
- *Am I listening so as to understand how this person's experiential reality has been socially constructed?*

- *Whose language is being privileged here? Am I trying to accept and understand this person's linguistic descriptions? If I am offering a distinction or typification in my language, why am I doing that? What are the affects of the various linguistic distinctions that are coming forth in the therapeutic conversation?*
- *What are the stories that support this person's problems? Are there dominant stories that are oppressing or limiting this person's life? What marginalized stories, am I hearing? Are there clues to marginalized stories that have not yet been spoken? How may I invite this person to engage in "insurrection of knowledges" around those marginalized stories?*
- *Am I focussing on meaning instead of on "facts"?*
- *Am I evaluating this person, or am I inviting him or her to evaluate a wide range of things (e.g. how therapy is going, preferred directions in life?)*
- *Am I situating my opinion in my personal experience? Am I being transparent about my context, values and intentions so that his person can evaluate the effects of my biases?*
- *Am I getting caught up in pathologizing or normative thinking? Are we collaboratively defining problems based on what is problematic in this person's experience? Am I staying away from "expert" hypotheses or theories?*

The infected and affected that I have worked with, usually have experienced rejection and derogation, low self-esteem, the pain of stigmatisation, loneliness, guilt, anger, fear for death and a range of other emotions. Their most basic need is for the therapist to create a climate in which they feel free to tell their story in a way they understand or not understand it. There must therefore be an openness to the need of the infected and/or affected. James Wharton (1981:49) has pointed out that:

> In the setting of catastrophic illness or trauma, it is inappropriate to preach at the patient. The appropriate attitude of ministry is one of care and compassion that is addressed to the stated needs of the patient [companion] or family member". (Emphasis mine)

Wharton therefore deconstructs the "top-down" position. The social-constructionist position and the continuous and conscious reflection on this position made me aware of the fact that doing therapy or research with the infected and affected is manifestly not a time or place to engage in an activity designed to proselytise, or to take advantage of the crisis situation to achieve some end chosen by the therapist.

In conclusion, ministry to the person(s) infected and or affected by HIV/AIDS should be responsive to the companions and should be a listening ministry for which the companion sets the agenda, a screen writing ministry for which the companion(s) become the actors, and an educational ministry in which they become the educators, and lastly a team ministry in which the therapist (researcher) becomes the facilitator who reinforces the ability, efforts and achievements of the companions. This position of the therapist being a facilitator, team mate or partner had encouraged and motivated people to take and keep control in their own hands. Most of the people with whom I have worked with in this research [and therapy] have prized their independence, and, especially, their continued control over their decisions and lives. This better and new understanding of my role as therapist and researcher came as a result, not only through my own reflection on it, but also as a result of the step I have taken to invite my co-workers (infected and affected, as well as the scientific community) to reflect on my position and role as therapist. Indeed a role that speaks of trust, honesty and subjective-integrity.

7.4 A CRITICAL REFLECTION ON A THEOLOGY OF HIV/AIDS

Suzette says:

> *Unlike my family, I never had any particular relationship with a church. Out of desperation I decided to attend a small evangelical church. When I spoke to the pastor he insisted that I repent of my sin. I walked out of that small church and decided never to sit foot in a church again.*

Another expressed him in the following way:

> *I hate it when people keep on telling me I must have faith, I must just belief and things will be better. I am a Christian – a committed Christian and I belief in the power of prayer – but … I mean … get real … I am having AIDS, I am dying … it's not if I am having a black spot in my face that can be washed away with a little bit of prayer water … they treat me as if I am not religious – I suppose religious people do not get AIDS …*

Reflecting on these two situations and others, the researcher came to the frightening reality that religious language and practices do not only liberate and lead to new perspectives and change, but it can also increase the agony of those infected and affected when it tries to offer religious "solutions" to the problem of suffering which do not help, but rather confine the sufferer to his/her (their) own isolation. Using the Bible, prayer, preaching or counselling as a theological means in such a way, no longer liberates, but becomes repressive.

The question that was asked by a great majority of those the researcher interviewed was: "*Why did this happen to me/sister/brother/father/mother*?" "*Have I earned this punishment*?" In these situations I was tempted to move in a role in which I could defend God and God's justice against the complains of both the infected and affected. It would have been easier to say: "*God knows what you going through*" or "*this is God's plan for you*" or even "*this is God's way of teaching you a lesson*", and even worst: "*God wants to bring you and your family closer to him*" (see chapter 3 for a more detailed view on this theology). The researcher rejects this theology as it places the responsibility for all the suffering on the suffering persons themselves. The person is turned into a victim, the perpetrator, the bad one or the sinner. Such theology promotes abstract theological concepts, but ignores the concrete life situation, suffering and hope of human beings. I perceive such a theology as an "un"-theology which has lost contact with reality and which does not display any solidarity with those who suffer (whether by self inflicted suffering or suffering inflicted on them by others). Such a theology in my opinion, lose sight of the concrete situation of misery and despair of those suffering from HIV/AIDS.

The researcher consciously retrieved from a theology that characterised God as a tyrannical God, a theology that sides with a God who "enslaves", "oppresses", "destroys" or justifies suffering. I would call this theology a "cybernetic-theology".

The theological position the researcher [therapist] champion in this research, is the one described in chapter 1 (1.2-3) that "learns people to see stories of the presence of God in their own lives" (Mitchel 1991:30). This view I would argue means: "finding connection between God's story and my story". The power of a storied or narrative-theology is brought to the forth by Thomas

Boomershine (1988-18) as he writes: “storytelling, particularly in the context of pastoral care relationship, becomes a sacrament, revealing God’s presence in the midst of tragedy”.

Some of the people the researcher has journeyed with have formed meaningful relationships with God, others, and themselves, which may not otherwise have formed. The HIV/AIDS crisis had in some cases led to a positive change in attitude, sexual practices and of a previously bad self-esteem. This indeed speaks of an immanent God, (a God present in our situations). It also speaks of the fact that where God’s story connects with our story – hope emerges.

In my looking back on what I would call “a reflection of a theology of HIV/AIDS”, three theological paradigms or practices emerge. These practices or paradigms became obvious during my interviews with the infected, affected and pastors. These are a:

- *First-order cybernetic theology of HIV/AIDS*
- *Second-order cybernetic theology of HIV/AIDS*
- *Social-constructionist theology of HIV/AIDS.*

In the ***first-order cybernetic theology*** of HIV/AIDS pastors give the impression that they are called by God to design a Spiritual strategic intervention that would interrupt the recurring patterns caused by SIN and direct the "sinners" to new behaviours through which they could achieve the divine goals God had given them (the pastors).

Pastors and therapists functioning in this paradigm, feel it's their responsibility to prescribe a spiritual "medicine" in the form of preaching, teaching or counselling. This leads to a theology of exploitation and spiritual abuse of those coming for "help". This model also strips theology from its integrity and turns the infected and affected into spiritual dysfunctional objects, and on the other hand, gives the pastor or therapist too much credit for any changes that might occur, while those they work with could be regarded "as passive recipients of external wisdom" (Freedman & Combs 1996:4).

One pastor from the Apostolic Faith Mission responded in a typical cybernetic theological fashion as he says:

> *I am in the ministry for thirteen years now, and never was I more convinced that God has given us a clear job description to bring his kingdom to its ethopia. AIDS is a consequence of sin – it's God's way of saying "I've had enough". My and your task is to lead people with AIDS to a road of repentance. Then, and only then, will God take his anger form the person … then, and only then can we send them away with the message of hope: "Go and sin no more …"*

The ***second-order cybernetic theology*** is perhaps the most practised model among pastors, ministers and therapists. This model attempts "to point the way to **a less** control-orientated model" (Freedman & Combs 1996:5) (Emphasis mine). This model does not place the one working with the infected or affected outside or above those coming for therapy or counselling. The emphasis is on "a less control-orientated model" which by implication says that the therapist is permitted to subtle manipulation of the other persons' story. One Methodist minister says:

> *People living with HIV/AIDS – we need to understand, are very emotional. So when they come to us for counselling they clearly request help. Many times these people are painfully aware of their sinful behaviour and wrong doings. They are looking for one who can help them deal with their guilt and the negative consequences of their behaviour. They come to us craving for the intervention of someone whom they can trust to help them. We need to respect and listen to them so they can confront their sin through confusion and repentance. We need to take them to God without them feeling we impose God on them.*

This model softens or flattens the hierarchy between therapist and those coming for therapy (or being researched), but still holds the view that the pastor or therapist knows better or more. The therapist (researcher) is still viewed as the objective catalyst that is there to provide insight, guidance, hope and encouragement, a reservoir of divine information, new insights and resources to offer to those coming for therapy. This subtle theology is summarized in the words of Wright (1995:60) as he writes:

> Over the past 20 years I've become convinced that as counsellors and ministers alike **we need to model for the counselees** what **we** are teaching or suggesting to them and be flexible that **we** can adapt to **their** thinking and communication style ... then based upon the **knowledge** of who **we** are and who the counselees are, **we** must adapt to speak their language.(emphasis:mine)

As in the case with *first-order cybernetic theology*, this *second-order cybernetic theology* reduces and distorts God's identity and takes integrity out of theology, research and therapy. Theology therefore becomes nothing more than a practice subjected to human manipulation, a power "tool" to manipulate research and therapy.

The theology I champion is the ***narrative-social-constructionist theology***. Much has been said about this approach or paradigm throughout this dissertation. This theology has forced me to reflect on God and Gods' providential care, God's calling and on my life. It compelled me to reject theologically unreasonable explanations of suffering and to reconceptualize

God and the divine presence and it made me to align myself with Clarks' (1986:40) thinking as he writes:

> We can reconceptualize God as a compassionate presence in suffering alongside those in pain or on the margins, as well as the ultimate source of empowerment for appropriate response.

This theology underpins the crucial role of unconditional love, understanding, acceptance, listening and shows compassion to the person as a human being and not an object. It helps the infected and affected to realize that their lives, in spite of the disease, have a value and a dignity of its own. In positioning myself in the *social-constructionist theology* frame of reference, I found that I have treated people as people and not as a "disease". It also taught me that HIV/AIDS can never define the person's entire being. The more I have worked from this understanding of what theology ought to be, the more I was reminded: that being connected to those around us, living or dead, is vital; and they coached me in terms of being a collaborator, not an expert, in peoples' lives. With about as much need to learn and as much expertise as they have.

Hence, I felt oppressed by the "cybernetic" versions of the God knowledge. Working with people from the perspective of seeing God as my co-worker, reassured me that "knowing" is not as important as love, active listening, actual participation and mutual sharing.

This indeed demonstrate the essence of a theology the Church, pastors and therapists should practice as Ellens (1987:21) puts it:

> with unconditional positive regard and with an acceptance and esteem which reflects [a theology that speaks of] God's unconditional grace.

People infected and affected don't need our theology. What they need is our partnership. The words of Kirkpatrick (1988:73) give an incredible perspective on this "not-knowing-not-expert" theological position as he writes:

> It is crucial that we should be able to hear what the people we are concerned with require, not what we, with the bias of our own needs, think is needed. We must hear what permission is being given us to release their potential for change, for growth. This will come through the strengths of their weaknesses, of their pain and its meaning.

One of the major problems facing the infected and affected (I have observed) is for **them** to find meaning in **their** experience, which has a value and use for **them**. In searching for this, what is needed is a space where they are not constantly confronted with a theology that supports feelings and attitudes of despair and hopelessness. This theology must lead people to "live out new self-images, new possibilities for relationships, and new futures" (Freedman & Combs 1996:16) as they become participants in the resurrection story of Jesus Christ.

7.5 COMMON PROBLEMS ENCOUNTERED IN THE RESEARCH

The problems experienced in this research were nominal and had no major impact on the research or on the way in which it was conducted. Nevertheless, minor problems were to some extend experienced in the following areas:

- The "recruitment" process
- Time constrains
- Report back
- A distorted image of narrative research/therapy.

7.5.1 The "recruitment" process

One of the most difficult tasks was to select the sample that would participate in this research. Initially the researcher decided to select a group/s of which the sample actually represents a specific population from which the infected and affected would come from. The researcher decided against it, as it would limit the research and reflect a bias. The researcher therefore had chosen to work with those infected and affected individuals and families who became co-workers and co-researchers on a voluntary basis. The researcher invited people (infected and/or affected) to become co-researchers, by advertising in the local newspapers. Over a period of almost nine weeks of intensive and expensive advertising, only four families responded (two coloured, a black single mother and one white family). An AIDS-hospice was approached and another two families availed themselves.

It was a struggle for the researcher to determine what constitutes an adequate, representable or sufficient, sample size. Unfortunately there was no clear-cut answer to this question. The researcher eventually decided that the small group was a large enough group on which a reasonable expenditure of time and energy could be spent. The researcher found the term "sufficient size" in narrative research relatively insignificant as the narrative researcher focuses on the quality of experiences and not necessarily on the quantity of experiences. The quality of a long-term relationship was valued more than the quantity of short-term relationships.

7.5.2 Time constrains

As already mentioned, this was a "hands-on" (field) research. A considerable amount of time was needed (and demanded) in order to have done the research and therapy with the integrity it deserved. Both quality and quantity time was demanded for the actual interviews, individual group (family) work, meetings with the scientific community as well as the writing up of the dissertation. Time constrains caused considerable (but manageable) amount of stress on the researchers' personal, social and family life, as well as his full-time work. This led (occasionally) to emotional, physical and sometimes even spiritual fatigue. This condition was nevertheless positive as it made the researcher aware of the fact that the researcher needed to suspend his time in order to spend time with his co-researchers. Time constrains caused to a large extend constructive tension that eventually led to self- reflection, self-therapy and self research and search.

7.5.3 Report back

Due to the extensiveness of the subject of research and the purpose of this study, all the stories that had been listened to, as well as the verbatim reports could not all be recorded in this dissertation. The research findings were comprehensive and the researcher intentionally recorded a “collage” of “story-parts”. These “parts” will hopefully become the sum of the total untold story of those infected and affected by HIV/AIDS (in this study).

The “story-parts” were not selected to fit in a particular sequence, but was rather selected on the basis of the flow of the story told in this dissertation. The researcher admits a bias in the selection of the “story-parts”. Not every category of infected or affected was covered in this research; for example, no drug abuse or homosexual stories are introduced here. The stories recorded in this study are therefore part of the story and not the story in itself. The stories and “story-parts” provided here, are an effort to make known to a wider audience the pain, suffering, satisfaction, and peace that people involved with HIV/AIDS have experienced and are experiencing. The researchers' intention is therefore to report on the effect of the devastating disease on those infected and affected, the responses of those infected and affected, those doing research and therapy, and the social-constructions obligation of those caring for those infected and affected.

7.5.4 A distorted image of narrative research/therapy

Whilst doing this study the researcher became aware of the many distorted "images" many caregivers have with regard to narrative therapy and research. Many of these distortions evolved from misunderstandings, deformed and uninformed understandings of what narrative therapy and research ought to be.

A pastor I've interviewed said:

> *I am not sure whether I feel comfortable with this approach … I mean … it's fine to listen to them and let them tell what's on their hearts and minds, but what do I do with that which I have listened to? Surely people come to us not to get involved in telling stories … I am not so sure whether such a "camp-fire-story sharing-approach" could be effective.*

This "re-telling of interesting stories" was most definitely one of the mentalities that caused narrative research and therapy to suffer a distorted image in this particular research. Another mentality was that this approach could be too scholarly. John Cornelson, a new minister in the Methodist Church expressed himselves as follows:

> *If one is not trained in psycho therapy, this method could be very difficult ... Imagine you listening to stories and not know what and how you need to listen ... You must know the clues as to how to make sense out of that information people will be sharing with you ...*

The two major interpretations, which led to distort understandings of what narrative therapy and research ought to be, are: that narrative therapy and research is **too simple**, and secondly, that it could be a **too complex scientific approach**.

Muller (1999:1) captures these distorted views beautifully as he writes:

> I hope that ... I will be able to clear up two misunderstandings. The first is that the narrative approach is only concerned with stories, as if all is needed is to collect and re-tell interesting stories... The second misunderstanding is that when people became aware of the narrative approach, they think that they need to be literary scholars

whose task it would be to analyse the stories according to scientific process.

These perceptions caused reluctance, scepticism and a non-interested attitude among many of my co-workers, especially among ministers and pastors. This awareness certainly encouraged the researcher to examine some of the dominant cultural "interpretational" ideas and practices that are contributing to many distorted views, interpretations and understandings of what narrative therapy and research ought to be. The researcher felt discouraged and demotivated at times, but convinced that this research will at the end, difficult as it might seem, make a worthwhile contribution to the way ministers, pastors as well as other caregivers will do therapy/counselling.

7.6 IN CONCLUSION

The researcher finds the reflective practice a valuable "tool" for critical evaluation. It encourages a process of continual learning, unlearning and relearning. It is a process that counteracts the hierarchy implied by our position, status and perceived role as therapists, the way we think and do research and therapy. It also challenges the researcher/therapist and co-workers to critically evaluate the non-social constructionists' beliefs, attitudes, perceptions, assumptions, stereo types, approaches, models and bias we might bring to therapy or research. This practice makes explicit and clarify the need for conscious and ongoing deconstruction.

Reflection has therefore the benefit of "facilitating" an active partnership, commitment and accountability between all co-workers, whilst making manageable the complicated task of deconstructing discourses, dominant experiences, attitudes, beliefs, practices that might cripple or paralyse the effectiveness of therapy and/or research. This, for the researcher, is a central practice in constituting the kinds of relationships, attitudes, ethics, beliefs, actions and practices that bring forth preferred ways of doing and thinking about those coming for therapy (in research), about research and therapy. Freedman & Combs (1996:287) describe the essence of reflection as follows:

> When we reflect ... on unique outcomes, on the effects of various practices, on preferred directions in life, or on any aspects of therapy [and research I would say] we are doing co-research [and co-therapy].

The researcher found that reflection promoted:

- *free conversation (spontaneously),*
- *open conversation (transparency),*
- *collaborative relationships,*
- *trust relationships,*
- *genuine curiosity and wonderment,*

- *a deeper understanding for each others stories,*
- *opportunities for new possibilities (new narratives),*
- *deconstruction of the therapists/researchers) position,*
- *evaluation of own emerging story and also of those of others,*
- *a context in which people become an audience to themselves and*
- *the understanding that people are experts in their own lives.*

Reflection in this research opened up space for the sharing of knowledge, experiences, for evaluative listening, for deconstructive questioning, and for the reconstruction of new realities, which eventually lead to the empowerment of all stakeholders of a shared reality.

My hope with this research is that it will inspire those working with HIV/AIDS infected and affected to discover within them an inner strength that will empower them to find that beneath the countless problems accompanied by the disease such as social rejection, self-pity, loneliness, feelings of being damaged, low self-esteem, worthlessness, lies, as Freedman & Combs (1996:xi) put it: “a sparkling uniqueness that will emerge as a meaningful striking contribution to the fabric of their existence”. My hope is that this study will become amongst other things, a process by which the therapist will work together with the infected and/or affected to dismantle the steely layers HIV/AIDS had formed around them, and in so doing opens up the options and opportunities for those infected to exercise an alternative choice over that which they experience as problem-saturated in their life stories.

The hope is that it will lead them to a point where they will be able, and empowered to say a prayer such as the following:

> *Almighty God, creator of life, sustainer of every good thing, I know my partner with me in pain of this earth, hear my prayer as I am in the midst of separation and alienation from everything I know to be supportive, and healing, and true.*
>
> *AIDS has caused me to feel separated from you. I say, "Why me, what did I do to deserve this?" … Help me to remember that you do not punish your creation by bringing disease, but that you are Emmanuel, God with us. You are close to me as my next breath.*
>
> *AIDS has caused a separation between the body I knew and my body now … Help me to remember that I'm more than my body and, while it pains me greatly to see what has happened to it, I am more than my body … I am part of you and you me.*

AIDS has separated me from my family … Oh God, help me and them to realize that I haven't changed, I'm still their child, our love for each other is your love for us … Help them overcome their fear, embarrassment and guilt … Their love brought me into this world … Help them share as much as possible with me.

AIDS has caused a separation between my friends and me; my friendships have been so important to me. They are especially important now … Help me oh God to recognise their fear, and help me them to realise my increasing need for them to love in any way they can.

AIDS has separated me from my society, my work, world and my community … It pains me for them to see me differently now … Forgive them for allowing their ignorance of this disease and their fear to blind their judgements … Help me with my anger towards them.

AIDS has caused separation between me and my church … Help the Church restore its ministry to "the least of these" by *reaching out to me and others … Help them suspend their judgements and love me as they have before … Help me and them to realise that the Church is the body of Christ … that separation and alienation wound the body.*

God of my birth and God of my death, help me know you have been, you are, and you are to come … Amen.

(Author unknown)